

Volume I – Research Component

A NARRATIVE AND SYSTEMIC EXPLORATION OF DEMENTIA AND SPOUSAL RELATIONSHIPS

Submitted by

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A Thesis submitted to the University of Birmingham in partial fulfillment of the regulations for
the degree of

Clinical Psychology Doctorate

Department of Clinical Psychology

School of psychology

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To 'HB'

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Volume II – Clinical Component

Clinical Practice Reports

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Contents – Volume II (Clinical Component)

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Overview of the thesis

This body of work represents partial fulfillment of the degree of Doctor of Clinical Psychology (Clin.Psy.D.) at the University of Birmingham.

Volume one represents the research component of the qualification, and is comprised of a conceptual literature review and a qualitative research paper.

The conceptual review analysed a small sample of the qualitative literature on couplehood and dementia. The analysis used Dialogic/Performance Analysis (Riessman, 2008) to provide critical commentary about the implications of participant voice, linguistic features and context in research papers, and how these may uncover possible narratives that are embedded in the literature. Implications of embedded narratives have been discussed.

The research portion is a piece of qualitative research that used Interpretative Phenomenological Analysis. The theoretical underpinning is that of Systemic psychology. Three couples were recruited (the husbands were all diagnosed with dementia). The couples have been presented as case studies showing themes that emerged between the partners in the couples. The discussion focuses on the perceptions of continuity/discontinuity in the relationship and shared and unshared narratives. Clinical implications and directions for future research have been proposed.

Volume two represents the clinical aspects of this qualification and is comprised of five clinical case reports: A case study using dual formulation, a small scale service-related research (service evaluation), single-case experimental design, case study and the abstract from an oral presentation.

Paper 1

The embedded narratives in qualitative research on couplehood and dementia:

A conceptual literature review.

By

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June 2012

Abstract

Aim:

This review serves to provide a commentary on the possible narratives that are embedded within the qualitative research papers on relationships and dementia.

Method:

Five qualitative articles were reviewed using Dialogic/Performance Analysis (Riessman, 2008). This conceptual literature review provides an interpretation of voice, linguistic features and contexts that play an active role in the creation of meaning and the possible narratives embedded within the literature.

Results:

A number of overarching narratives were found embedded across the research, specifically the Medical, Morality, Relationship and Psychological Process narratives. A number of sub-narratives were also identified.

Conclusion:

The review highlights the need for researchers to be more transparent about the epistemological, theoretical and personal factors that impinge upon how they engage with the data and present their findings. It also highlights the need for readers to engage with research papers in a more active manner by being aware of their own biases on the creation of meaning and interpretation.

Keywords: dementia, couplehood, narratives, Dialogic/Performance Analysis

INTRODUCTION

It is through the process of creating, narrating and listening to stories that the essence of narratives lies. They are socially constructed. Meaning is created through the performance of an I-Thou relationship (Bakhtin, 1975). Through dialogue¹ we share experiences and create meaning and seamlessly transition between roles of narrator and listener². The identities of narrator and listener are both positioned and performed with a targeted audience in mind (Riessman, 2008). Stories are inescapable; we have been raised on stories and are bombarded by stories of all kinds and through all forms of media, including research.

The word *history* originates from the Greek word '*historia*' meaning 'narrative' which is derived from the word '*histor*' meaning 'learned, wise man' (Concise Oxford English Dictionary, 2011, p. 676). Thus history itself indicates that even the recollection of 'true' historical events is told and retold through a 'voice' or position, *his* voice highlighting a linguistic bias that speaks to gender and social inequalities that are located within temporal and cultural contexts and values. However in our daily reading, telling or hearing of narratives, we very rarely pay attention to context. For example 21st Century British society still generally associates notions of caring and caregiving with female roles and we may not question why research on caregiving in dementia is primarily represented by female caregivers. Similar issues can be found in psychology and research which have predominantly reflected various biases of a privileged set of society, or a particular view of disorder and psychological experiences - the medical model continues to be a prevailing perspective. It is such contexts

¹ Or text

² Or reader.

that we take for granted in our everyday lives and reading, but they are active agents in the creation of meaning and in the performance of the narratives that we intend to share and those narratives embedded beyond our intentions. The notion of voice has been a central feature in qualitative research on dementia, with a recently increasing interest in providing voice to the person with dementia (PWD) and to the 'couple voice', as a voice distinct from that of both partners. This highlights the multi-voiced nature of narratives. Work by Forbat (2003) highlights how voice and positioning are active agents in the construction and preservation of narratives, identity and meaning. The existence of plural voices, each of which is positioned, underscores the need for a closer examination of what is being said, to whom and for what purpose. Such an examination may highlight hidden narratives, silenced or whispered voices, and locate gaps and biases.

We take words for granted, yet language is not a passive but an active tool by which narratives are performed and represented. Linguistic features are active strategies chosen by the narrator to convey a specific message to a targeted audience. In fact, the audience's reaction is implicated in the very process of telling stories (Riessman, 2008). Language is thus more than just a tool by which we communicate, it is a tool by which meaning is created and interpreted³. Every interpreter has their own unique voice. Language is a tool that is clearly impacted by cultural norms, social values and psychological factors, and thus the meaning that is created is subjective and a single story is open to many interpretations.

³ Psycholinguistics is the study of the influence of psychological factors on the formation, practice and the interpretation and understanding of language.

Therefore a close reading of linguistic features such as specific words used, frequency of word usage, direct speech, engagement with the audience, and verb tense (Riessman, 2008) are all saturated with ideology and meaning. Language is never uncontaminated, and brings with it a history of use that has privileged certain voices and silenced others. Riessman (2008) proposes that every statement, whether spoken or written, conveys hints of past narratives. Thus it is necessary to move beyond a simplistic, unsophisticated and unconscious reading of research papers, and pay active attention to the linguistic features, contexts and the performance of voice, positioning and identity within papers as they are soaked with meaning.

Linguistic devices such as rhetoric and metaphor serve as a means of persuading the reader to interpret a specific targeted effect, and create and confer meaning without making the implicit meaning explicit. Such figures of speech also point to the shared conventions of narratives. These are just two of a plethora of linguistic devices that story-tellers use to create meaning, however they are rarely noticed and their presence and effect are rarely questioned. Through such conventions, the narrator and listener are able to produce meaning and continuity without being overly concerned with every possible scenario. However the meaning of an experience in its purest form is often diluted. Riessman (2008) argues that all narratives provide an oversimplification.

Narratives are contextual with multiple layers; those that are visible and explicit and those that are implicit and hidden. All stories have a narrator who chooses and positions the audience, the sequence and the content, and through these creates the intended meaning. By their very nature, stories are sequential and temporal, act as social artefacts and reflect truths of a specific time. However what is considered truth at one time, context or culture may not hold true for a

different time, context or culture. However historical ‘truths’ are carried forth in narratives, which sometimes become embedded beyond plain view – yet still have a powerful influence on the performance of identity and voice. I propose that research articles are narratives, like stories, are laden with more than just the intended narrative or presented findings. Research papers are saturated with embedded narratives that reflect larger stories about society and culture, personal and collective experience and methodological and theoretical frameworks. Whatever the ideological and methodological framework, all stories are presented in narrative sequences and structural conventions common to all stories. An investigation of the various structural components may reveal the contexts in which the research is embedded.

This review is yet another narrative and follows narrative conventions. The concepts and ideas chosen for study are reflections of the development of ideas over time, or determined by social and cultural ideas of what is important in a particular context. I propose that every paper represents more than just the participants’ experience.

Historically dementia has been primarily understood through a biomedical and deficit model which has been concerned with symptoms and burden of caring. However, work by Kitwood (1997) played a fundamental role in a shift away from biomedical and stress-burden models of caring to a more person-centred approach. However, this has usually not included the ‘voice’ of the PWD, which is highlighted by the lack of research done with couples where both the spouse caregiver and the PWD are included. In recent years there has been an increasing interest in what happens to relationships in dementia particularly from a qualitative perspective; and with particular aims of giving voice to the PWD and the couple.

One of the issues this review aims to illustrate is that every research paper is uniquely influenced by the context of the study which it reports, as well as by its participants and the epistemological and theoretical position of the researchers. Researchers may not always be aware of the way their own socio-political context influences their choice of research question, methodology, analysis and the language chosen to report their findings. Illustration of such influences may serve to highlight that research does not uncover an objective 'truth'. It may also highlight the need to take a critical perspective on researching, reporting of research and reading of research, in order that we can see such influences more clearly.

Research articles may appear to have similar embedded narratives such as the commonly accepted illness or medical narratives; however, a closer critical reading and interpretation of linguistic features, voice and context may reveal different foundations to these narratives. It is the larger research and clinical milieu in which researchers are embedded that ascribe interest and accessibility to a particular context at a particular time, and which may impact the interpretation of particular embedded narratives.

This review aims to expose and illustrate the mechanics of how narratives and positions develop and build on pre-existing narratives. This review proposes that some ideas such as relationship continuity can be perceived and interpreted as narratives that have developed over time. Our knowledge of relational continuity/discontinuity for example has been shaped by previous research and may appear to recur, develop and become elaborated upon over time or from paper to paper. The development of ideas and knowledge is predicated on previous knowledge as well as being influenced by contextual factors. It could also be that recurrent references to existing research is strategically used by researchers to position themselves with

or against previous research, as a means of persuading readers of the credibility and novelty of their positioned findings. For example, researchers wishing to stress a positive narrative may counterpoise themselves to heterogeneous research. While efforts can be made to bracket off preconceptions, it is impossible to unlearn what we already know.

Traditionally dementia research has taken a biomedical view (Clare, 2002; Kitwood, 1997; & Phinney, 1998). This review aims to explore how such widely accepted positions/narratives may have an implicit and explicit impact on subsequent research and possible embedded narratives. This review proposes that privileging particular voices or narratives such as those expounded by the medical paradigm, while helpful, may not provide a holistic story about the experience of dementia. Aspects such as the impact of dementia upon spousal relationships, with a focus on relationship dynamics risk conscious or unconscious exclusion. This review thus invites researchers to be more conscious about the language with which they convey their research stories and the larger prevailing contexts in society and health care.

Recent dementia research has begun to move away from the biomedical or stress-burden models (McGovern, 2011). This may be seen in how researchers are representing caring relationships in their research, demonstrating a shift away from stress-burden models to ones that focus on more positive conceptions of caring including continuity in the spousal role. It may also be reflected in the different theoretical and methodological approaches that researchers are employing.

Traditionally the predominance of caring relationships being represented by female carers is arguably a product of the prevailing socio-cultural context which may introduce intentional or

unintentional narratives. Such narratives may or may not resonate or represent spouses and couples who do not prescribe to the prevailing culture and thus may not be particularly helpful for them. The position of the researcher could also impact the possible narratives that are embedded in the literature such as the perceptions of marriage, traditional gender roles or views on relationships and aging.

In the research on dementia and couples, the voice of the PWD and the couple voice are not always well represented. This may be due to the methodological approaches employed by researchers which intentionally or unintentionally privilege the voice of either partner. Meaning is often created through the use of language and linguistic features, which may influence the tone of the paper or privilege particular voices or positions. As such this literature review serves to demonstrate a need for researchers to pay more attention to language, linguistic devices, methodological and theoretical approaches and voice in order to understand how these may influence the interpretation of embedded narratives. It offers an invitation to researchers and readers to take a critical perspective in the reporting and reading of research as a means to see these influences more explicitly.

METHOD

Aims

I was interested in the narratives embedded in qualitative research on dementia and spousal relationships. However in order to restrict this to a manageable enterprise and because of the recent interest in the voice of the PWD and the couple's voice (as opposed to the carers' voices), I focused on qualitative research in which both members of the couple were

interviewed about the relationship. The overall aim was explored through a consideration of the representation of voice, the language used and the underlying contexts.

The research question

What are the narratives embedded in the qualitative literature on relationships and dementia?

Search Strategy

A preliminary systematic search of the literature using the following databases was conducted: Embase (1974-2012), Ovid MEDLINE (R) (1980 -2012) and PsycINFO (1967 to week 3 July 2012). The primary inclusion criteria were that the research was qualitative, that both the person with dementia and their spouse/partner were interviewed, and the focus of the interview was the relationship itself. The search terms used, together with the results of the search, are shown in Table 1 (see also Figure 1 for flow chart). This yielded six articles from peer reviewed journals. Papers which were not research articles were excluded, leaving four articles. Papers relating to institutionalised spouses were also excluded as the literature review was a preliminary step towards the research paper presented in this thesis, which explored spousal relationships where both partners lived in the couple's home, leaving two papers both by Hellstrom, Nolan and Lundh (2005a, 2007).

Table 1. Preliminary systematic literature search

Step	Systematic Search strategy	Number of articles
1	Dementia*	49672
2	Alzheimer*	39233
3	1 OR 2	69065
4	Wive* OR wife* OR husband* OR spous* OR partner or couple	111046
5	Couplehood	47
6	3 AND 4	1737
7	5 AND 6	6
8	Exclude 2 non research papers	4
9	Exclude 2 papers on institutionalised spouses	2

The reference sections of these remaining two articles were hand searched yielding a further seven articles, which represented a range of themes present in qualitative research on couplehood. In peer supervision a further two articles published in 2011 were identified and included. The total number of articles was thus 11 (Appendix 1). From these 11 articles, five were selected for review. These are detailed in Table 2. Four of the nine articles identified subsequent to the database search were excluded because they did not meet the inclusion/exclusion criteria (e.g. Walters et al., 2004, did not interview both parties; Clare & Shakespeare, 2004, did not focus on the relationship; Davies & Gregory, 2007, was not a research article, and Davies, 2011, used a mixed methods design). A further two (by Hellstrom et al., 2005a, 2005b) were excluded because they used the same data as that reported in the later 2007 paper (and so might be expected to share very similar narratives). This left 5 papers for review. Work by Riessman (2002, 2003, 2008) illustrates that the interpretation of narratives does not pertain to the sample size or topic area, but to the researchers consideration of voice, linguistic features and context. As such this review method can use small sample sizes and be used across subject disciplines.

Figure 1. Flow chart depicting search strategy

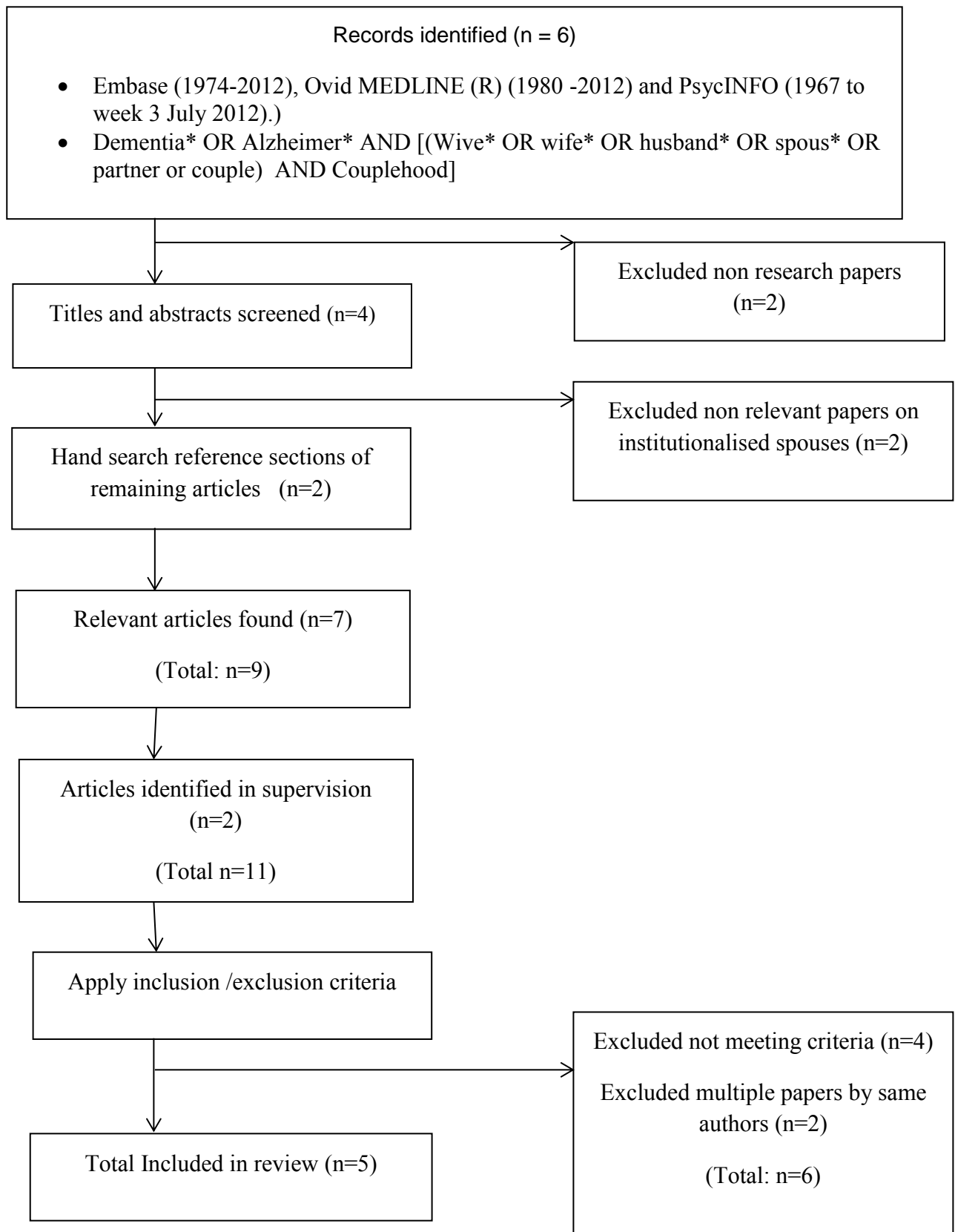


Table 2. The final five selected papers

Author / Date	Location	Demographics	Method	Epistemology	Theoretical Approach	Key Findings
Svanstrom & Dahlberg (2004)	Sweden	Heterosexual married couples (n=5)	Qualitative Reflective Life Research Written diary and Interviewed separately	Phenomenological	Atheoretical Life world theory	“Relationship Essence” characterised by <ul style="list-style-type: none"> • Imbalance in responsibilities • Futility • Hopelessness • Homelessness
Robinson et al. (2005)	Wales, U.K.	Heterosexual married couples (n=9)	Qualitative IPA Interviewed together	Phenomenological	Systemic / Family systems	“Themes” Making sense and adjusting to loss: Higher Order Theme 1: Not quite the same person, tell me what actually is wrong Theme 1. You don’t notice straight away Theme 2. Coming to the conclusion Theme 3. I quite accepted it Theme 4. It did nothing for me Theme 5. Coming here helped Higher Order Theme 2: Everything’s changed, we have to go from there Theme 6. I would say I have changed Theme 7. Taking over the reins Theme 8. Take it as it comes Theme 9. I wouldn’t mind doing it all again.
Daniels et al. (2007)	Nebraska & East Carolina, U.S.A.	Heterosexual married couple (n=1)	Qualitative Single case / longitudinal	Social constructionism	Narrative Approach	“Themes”: Theme 1. Perspectives and Preparation for Future Change Theme 2. Family Influences and Social

			Holistic Content Narrative Analysis			Support Theme 3: Theme 3. Life Evaluation Theme 4. Experiences with AD
			Interviewed together			
Hellstrom et al. (2007)	Sweden	Heterosexual married couples (n=20)	Qualitative Grounded Theory Longitudinal Interviewed together initially, then separately	Constructivist	Relationship -centred	“Relationship Phases”: Phase 1: Sustaining Couplehood <ul style="list-style-type: none"> • Taking things through • Being affectionate and appreciative • Making the best of things • Keeping the peace Phase 2: Maintaining Involvement <ul style="list-style-type: none"> • Playing and active part • Taking risks • Handing over • Letting go • Taking over Phase 3: Moving On <ul style="list-style-type: none"> • Remaining a ‘we’ • Becoming and ‘I’ • New beginning
Molyneaux et al. (2011)	Liverpool, U.K.	Heterosexual couples [Married (n=4),unmarried (n=1)]	Qualitative Interviewed together	Constructivist	None identified	“Themes”: Theme 1. Shifting identities within couplehood Theme 2. Maintaining the relationship despite dementia Theme 3. The good old days Theme 4. Technically being a carer Theme 5. Sharing the experience of dementia

It is proposed that the selected papers are illustrative of the differing positive or negative perceptions of dementia, and a range of ideas and issues found in dementia research. The papers also have the potential to act as exemplars of different socio-cultural political contexts, theoretical positions and the development of ideas over time. As the papers are presented as exemplars, this review does not make claims with regard to their evidential value, representativeness or breadth of the included literature.

The tone of the Svanstrom and Dahlberg (2004) and Hellstrom et al (2007) papers may represent exemplars of differing and/or developing perceptions in dementia research over the years. For example, Svanstrom and Dahlberg's (2004) paper may act as an exemplar of dementia research that portrays a distressing and negative side of the impact of dementia on couples, whereas Hellstrom et al. (2007) represents a generally positive account of dementia and relationships.

The selected papers also represent a range of issues commonly found in dementia research. Svanstrom and Dahlberg (2004) illustrates ideas about the impact of dementia on the *quality of relationships*, a topic that has been widely studied (Quinn, Clare & Woods, 2009; Walker & Luszcz, 2009). The focus on *loss* in Robinson et al. (2005) represents a common theme in dementia research (McGovern, 2011) and commonly held ideas about aging. Daniels et al. (2007) focusses on the idea of *commitment*, a relationship factor that has been shown to have an impact on relationships (Davies & Gregory, 2007). Hellstrom et al. (2007) represents ideas of *couplehood* and *continuity/discontinuity*, ideas that are present in recent dementia research (Walters et al., 2010). Finally the Molyneaux et al. (2011) paper focuses on *identity*, which is a prominent concept in dementia research (Cadell & Clare, 2010).

The range of geographic locations across the different papers (Table 2) may act as exemplars of the effect of socio-politico-cultural environment on the development and interpretation of narratives.

The papers could also act as exemplars of how theories (Table 2) impact on the interpretation of narratives. Svanstrom and Dahlberg (2004) uses *Life World Theory*, which has its basis in the biological sciences and moral reasoning. The *systemic* focus in Robinson et al. (2005) and Hellstrom et al. (2007) and the *narrative* focus in Daniels et al. (2007) may represent a move away from traditional medically based conceptions of dementia. The Molyneaux et al. (2011) may represent papers which claim to have *no theoretical* underpinning⁴.

The date range (2004-2011) of the selected articles illustrate the development of narratives over time. While it may be said that publication date may partly be determined by long publication cycles, the knowledge contained within those articles would only be available to a larger clinical and research population once published, whether on paper or on-line. As such, the articles have been presented in this review in chronological order.

⁴ Svanstrom and Dahlberg (2004) also claim to be 'atheoretical' despite using Life World Theory.

Analysis

Riessman (2008, pp. 108-140) demonstrates that there is no one particular way of conducting dialogic/performance analysis, rather it is determined by how the investigator chooses to engage with the text. I chose to analyse my papers in a systematic manner. For example, each article was read numerous times to acquire a general understanding and an appreciation of its position in the broader context of all the selected papers. Subsequent readings attended to aspects such as linguistic features, voice and context and how these affected the construction of the narratives (Table 3). Certain linguistic or contextual artifacts (e.g. gender-biased language or theoretical/epistemological biases) lay within the structure and performance of narratives (Riessman, 2008). These artifacts revealed embedded narratives, either intentional or unintentional. Thus the analysis focused on exposing possible embedded narratives through the analysis of how these artefacts are “produced” in each paper. As this is a particularly idiographic approach, other investigators may interpret the performance of such artifacts differently as well as identify others or not select those chosen in this review. However there are a number of steps that I used that would allow others to replicate the procedure. For example, the method aims to provide transparency about how I engaged with the texts, and thus essentially requires that I demonstrate how I reached my interpretations. As such, excerpts from the text have been provided as exemplars of my interpreted narratives. These interpretations were taken back to the original texts to determine plausibility in the overall structure of the text, and were further reviewed in supervision to determine plausibility. Narratives with similar characteristics were grouped in an overarching narrative structure comprising a number of sub-narratives as determined by the specific contribution of voice,

linguistic features and context. A position statement is also provided as a means of being transparent about influences in my life that may help the reader contextualise my interpretations.

Table 3. Dialogic/Performance Analysis steps

Analytic Steps	Description
1. Reading and rereading of all selected articles.	Acquire a general understanding of each paper in the broader context of all the selected papers.
2. Analyse article paying particular attention to Linguistic Features.	Extract exemplars of linguistic features such as metaphor, rhetoric, gender-biased language, the etymology, definitions and repetition of words.
3. Analyse article paying particular attention to Voice	Extract exemplars of the representation of voice. This may include the researchers' or participants voice. Determine the position of the paper by analysing aims of the research and how they position themselves in relation to other papers. Consider contextual influences.
4. Analyse article and pay particular attention to Context.	Extract examples of researcher influences, settings and social circumstances.
5. Review extracted material, and develop narratives.	Using extracted material interpret narratives. Take narratives back to the article to determine if they fit within the findings of the paper. Review narratives in supervision.
6. Move to next paper.	Systematically complete steps 2-5 for each paper.
7. Develop overarching narratives and sub-narratives.	Search for connections across narratives. May include development of ideas over time and across narratives.

The three main tenets of the analysis are briefly described below:

Linguistic Features. Words are the tools by which narratives are conveyed and structured. This method of analysis “interrogates how talk among speakers is interactively (dialogically) produced and performed as narrative” (Riessman, 2008, p. 105). This focusses on what and how narratives are spoken/written. Linguistic features such as the use of speech to convey messages about one’s positioned identity, the use of repetition as a means of punctuating something significant, and shifts in verb tense as a means of either focusing attention on specific aspects of the story may all contribute to embedded narratives (Riessman, 2008). According to Riessman (2008) the etymology of words invokes meanings and may be used to actively position the audience; thus the very choice of words may uncover implicit or explicit intentions. Other linguistic features include shifting pronouns, definitions, metaphors or rhetoric as a means of persuading the reader to a particular view.

Voice. The concept of voice is related to positioning (Hermans, 2002, p. 147). The focus of positioning theory is on the dialogic interactions in how people are positioned and position themselves (Harre, Moghaddam, Cairnie, Rothbart & Sabat, 2012) in the creation of shared meaning (Chatterji, 1998, p. 375) and identity (Josephs, 2002, p. 161). As narratives are narrated by positioned narrators, they reveal something about the narrator (Sperling, Gilyard & Freedman, 2011, p. 76) such as socially ascribed roles/positions (Josephs, 2002, p.162). Riessman (2008, p. 111) proposes that voices reflect “positioned identities”, which could be related to the identities and roles of the researchers, participants, targeted audience, or various contexts described later. This highlights the *polyphonic* and *dialogic* nature of narratives (Riessman, 2002, 2008). In the case of research papers, the findings are authored and narrated

by the researchers. This process of narrating highlights how the voice of the participant is appropriated and mediated (Chatterji, 1998, p. 258) through the researchers' voice. This potentially highlights how the aims and purposes of the researchers may intentionally or unintentionally privilege or silence some voices (Sperling et al., 2011, p. 71). As the experience of dementia can be understood through the concept of voice (Chatterji, 1998, p. 357) the representation of whose voices are heard at a micro level is an important consideration, especially in the light of recent trends toward aiming to represent the voice of the PWD and couple (McGovern, 2011).

On a macro level, voice may be related to the social-cultural contexts that impact the construction of those identities (Josephs, 2002, p. 163). Such 'cultural filters' (Riessman, 2008, p. 111) are not only clues to underlying contextual influences (Sperling et al., p. 73) but are voices in and of themselves, and represent the voice of the various contexts in which the research is reported. Voice therefore highlights the dialogic link between individual identity (micro) and larger social identity (macro), i.e. the interaction between the voices of the individual and context (Josephs, 2002, p. 161). For example, the voice of the narrator, participants and targeted audience may be implicitly or explicitly impacted by the voices of 'institutional settings' (Hermans, 2002, p.149), 'ideology' (Sperling et al., 2011, pp. 70, 76), socially prescribed 'roles', cultural belief systems, geography, time and language (Josephs, 2002, pp.162-166) and may highlight dominant power structures (Josephs, 2002, p.171). Thus voice is closely linked with the types of contextual influences discussed later.

Another aspect of voice relates to the linguistic focus of how something is spoken or written. It is used to describe things such as writing style, authorship and language (Sperling et al.,

2011, p. 70). Language is also mediated and embedded within larger social and cultural contexts or ‘mechanisms of power’ and may highlight how particular voices are privileged or maintained (Sperling et al., 2011, p. 75) for example, medical or gender-biased language.

Voice is situated within historical and social contexts, thus the voice of researchers can be influenced by other voices previously heard in research (Sperling et al., 2011, p. 72), and thus the voice of the current researchers may be influenced by those previously heard voices.

Context. As shown above, contextual influences impact the construction and representation of voice. Riessman (2008) advocates that stories are composed and received in contexts, and convey messages about society, culture, people and groups (ibid), and thus Dialogic/performance analysis requires a critical reading of context. Context may include things such as the influence of the investigator, setting and social circumstances (Riessman, 2008, p. 105).

Not every paper explicitly attends to every type of possible context, and each reading may offer up a different interpretation. Consideration of context will partly be determined by whether the authors have made various levels of context explicit, as well as through the investigators’ interpretation of things such as geographic location, institutional settings, theoretical and epistemological positions. Other possible contexts may reflect implicit or explicit ‘structures of inequality and power’ such as gender (Riessman, 2008, p. 115) and religious values.

Position Statement

As a factor of dialogic/performance analysis, and in acknowledgement of the inescapability of my own narratives, I feel it is essential to provide a context that may have influenced the

manner in which I perceived and interpreted the narratives. This is my attempt to make the implicit more explicit so that you can contextualise your reading. This review itself is a narrative; and like all narratives, I am a positioned narrator and have used the commonly accepted narrative structure, to tell my story to you, my audience. In my clinical and professional work I am heavily influenced by systemic and narrative ideas and subscribe to ideas of social constructionism. I have lived in five countries and three continents, and I feel that this may have made me more acutely aware of the influence of socio-cultural-politico contexts and language on my interpretation. I have also had an interest in literature, psycholinguistics and the development and use of language. Having lived, worked and studied in the United States for a number of years before moving to the United Kingdom, I am particularly acculturated to American culture. I appreciate that this may give rise to a strong sense of independence and the right to choice as a fundamental premise of my autonomy. I have also lived in developing countries, which has influenced my focus on power dynamics, autonomy, giving voice to less dominant voices and revealing the pervasive dominant narratives that are embedded in our everyday lives and academia, yet which we may not explicitly recognise. Although not conservatively so, I am a practicing Christian. One of the influences of my faith is for seeing life as a journey, and for viewing relationships as positive and continuous. I am positively biased towards working with older adults and have had very positive and encouraging experiences of older adults, personally and professionally.

REVIEW OF THE LITERATURE

A brief description of the aims and summary of the findings is presented to provide an understanding of the structure in which the narratives are embedded. The discussion of the analysis will be discussed in two parts. The first part will discuss preliminary considerations of the aspects of the voice and context. This discussion of voice will consider issues such as the representation of participant's voice, the voice of the narrator and voice as a positioning tool in the selected papers. The discussion on context will outline the different types of contextual influences found in the papers such as researcher influences, settings and social circumstances. The second part will then illustrate the narratives found embedded within the papers by providing specific examples of how voice, linguistic features and contextual factors (where applicable) have contributed to the interpretation of the narratives.

The selected papers

The aim of the Svanstrom and Dahlberg (2004) paper was to investigate the experience of dementia on spousal relationships. According to the researchers, the 'essence' of couples' lives affected by dementia was characterised by a 'heteronomous existence' (p. 677) and characterised by four themes (Table 2).

The aim of the Robinson et al. (2005) paper was to explore couples' psychological reactions to a diagnosis of dementia. The researchers proposed a process-oriented model of loss based on their findings, which were characterised by an overarching theme of 'making sense and

adjusting to loss’, and two subsumed higher-order themes. Each of these higher-order themes incorporated five further themes (Table 2).

The aim of the Daniels et al. (2007) paper was to explore how a couple creates a shared story about the experience of dementia. According to the researchers the couple’s story was characterised by ‘positive reflections’ and a ‘lifelong commitment’. Furthermore they presented four themes around which they felt the couple’s story was centred (Table 2).

The aim of the Hellstrom et al. (2007) paper was to explore how couples experience dementia and how it impacts their relationship over time. The researchers propose a three phased model characterised by couples actively working at creating and maintaining couplehood despite dementia (Table 2).

The aim of the Molyneaux et al. (2011) paper were to determine how couples co-create their understanding of dementia and the impact of dementia on the relationship. The researchers propose that the co-construction of couplehood in dementia can be represented by five themes, which highlight how couples jointly and actively worked at maintaining a sense of couplehood (Table 2).

Voice

While it is the voice of the researchers’ that act as narrators of their findings, they are not the only voice present. Others could be related to the voice of the research participants, the targeted audience or larger social contexts (Riessman, 2008, p. 106). This highlights the polyphonic nature of voice and position proposed by Riessman (2008, p. 107). As discussed

earlier, voice is a complex dialogic interaction between individual voices and social and cultural factors (Sperling, 2011, p. 73). So despite the aims of representing the participants' voice (in this case the voice of the PWD, their spouses and the couple voice), these voices may be mediated or appropriated by factors such as methodological problems, the researchers' voice/position, linguistic features or voices that represent particular contextual influences.

Methodological Problems

A number of methodological problems complicate the view and representation of voice within the reviewed papers. In Svanstrom and Dahlberg (2004) the methodology of using diaries that were managed by the well spouse, seems to make assumptions about people with dementia perhaps not being able to manage the diaries or their cognitive abilities. This is arguably privileging the voice of the well spouse. Furthermore agreement to participate was made with the healthy spouse and both the interview and analysis began with the spouse without dementia; potentially biasing whose voice is heard and the impact of this on any resultant emerging themes.

In Svanstrom and Dahlberg (2004) and Daniels et al. (2007) there are occasions where the researchers have not made clear which participant said what. As quotations are not attributed to a specific participant, it could be questioned as to how representative those quotes are of the sample as it could be that one participant is being quoted repeatedly. It could be that the voice of a particular PWD or spouse was favoured over others as they supported and confirmed the authors' views. In the latter paper, the unattributed quotes refer to the couple voice.

Representation of voice is also complicated in Svanstrom and Dahlberg (2004) where the voices of the PWD and their spouse have been paraphrased and not presented as direct

quotations. Without direct quotations to illustrate some strong points that are made, it is not possible for the reader to feel confident in the interpretations.

The role of interpretation can be seen in two papers. Svanstrom and Dahlberg (2004) present information from people who chose not to participate in the research and speculate about the impact of dementia on these relationships, without having interviewed these couples. Similarly in Daniels et al. (2007) the couple voice is occasionally represented by the researcher's interpretations of the visual analysis of interactions between the couple and not verbal communication.

Other methodological problems may include having lost or gained meaning through the translation from Swedish to English as in the Svanstrom and Dahlberg paper (2004) and thus not being clear what impact the voice of the interpreter may have had on the interpretation.

The unequal representation of voice is a pervasive problem. Daniels et al. (2007) and Molyneaux et al. (2011) are the only papers to address this. However both underplay its influence. In Daniels et al. (2007) the researchers' acknowledgment that the PWD was more cognitively impaired than originally expected and that the well husband would talk over his wife and respond on her behalf (p. 169) or interject in conversations claiming that his wife could not remember (p. 171). They use this explanation as justification for the unequal contribution of voice between the PWD and well spouse. In Molyneaux et al. (2011), despite the researchers acknowledging that there had been unequal contributions by partners, the paper still presents examples that are more-or-less equal in the contribution of each partner per dialogue. This could suggest the

researchers' bias towards showing relationships positively as being equal and reciprocal, rather than showing the extracts that demonstrated the inequality.

The Researcher's voice

As shall be seen later in the discussions on context, the researcher's theoretical position provides a context or lens by which data are analysed and reported. It is thus important to think about such theoretical influences as it is the researcher's voice that narrates the research.

Voice as positioning

Research and narratives develop over time, where new research builds on previous research. This may reflect research conventions of storytelling that require the building of a rationale in the background to research papers. Thus the voices that narrate research intuitively impact future research. In Hellstrom et al. (2007), the model on couplehood dynamics resembles the dynamics and 'work' espoused by Keady (1999) and Keady and Nolan (2003), while the 'moving on' phase of either 'remaining a we', or 'becoming an I' seems particularly reminiscent of the typology championed by Kaplan (2001). The focus on temporality and continuity/discontinuity resembles work by Chelsa, Martinson and Muwaswes (1994) where both partners work at sustaining the relationship. Similarly the influences of the Hellstrom et al. (2007) paper on the Molyneaux et al. (2011) paper which present ideas relating to identity, continuity and maintaining relationships, are clear. In Svanstrom and Dahlberg (2004), the methodology of 'reflective lifestory research' and the analysis process was predicated on principles described by one of the researchers in one of their previous papers – clearly being influenced by and developing on their own research.

The Hellstrom et al. (2007) and Molyneaux et al. (2011) papers position themselves in opposition to Svanstrom and Dahlberg (2004). They do this by explicitly stating that their research “bear little resemblance to the work of Svanstrom and Dahlberg (2004) who depict ...an unbalanced life characterised by feelings of futility, hopelessness and loneliness” (p. 404). By actively distancing themselves from the accounts given by Svanstrom and Dahlberg (2004) they are making a position statement about their view on the relational impact of dementia being more positive.

For Riessman (2008) words represent and reflect positioned identities that can be used as a means to create a tone that may persuade the reader to a particular interpretation, in this case about the impact of dementia. The two papers are polarised on their positions. Svanstrom and Dahlberg (2004) portray a negative and distressing view of the impact of dementia, while Hellstrom et al. (2007) portray a more positive optimistic position. In both these papers the tone and position is created through the use of language (Box 1).

Box 1: The use of language in creating a tone

Svanstrom and Dahlberg (2004):

‘vulnerable’ (p. 676), ‘imbalance’ (p. 676), ‘futility’ (p. 676), ‘hopelessness’ (p. 676), ‘lost’ (p. 677), ‘insecure’ (p. 677), ‘uncertainty’ (p. 677), ‘loss’ (p. 677), ‘confused’ (p. 677), ‘discomfort’ (p. 677), ‘awkwardness’ (p. 678), ‘perplexity’ (p. 678), ‘powerless’ (p. 678), ‘futile’ (p. 678), ‘disinterested’ (p. 679), ‘lonely’ (p. 679), ‘loneliness’ (p. 679), ‘humiliated’ (p. 679), ‘difficulties’ (p. 681), ‘struggle’ (p. 681), ‘unbalanced’ (p. 683), ‘stressful’ (p. 683), ‘burden’ (p. 683), ‘suffer’ (p. 684), ‘threatened’ (p. 684), ‘suffering’ (p. 685), ‘lack of freedom’ (p. 678), ‘life is over’ (p. 680), ‘no choice’ (p. 680), ‘heavy burden’ (p. 683), ‘the restricted nature of these couples’ lives’ (p. 684)

Hellstrom et al. (2007):

‘ingenuity’ (p. 390), ‘flourish’ (p. 390), ‘balance’ (p. 390), ‘purposeful’ (p. 390), ‘strengths’ (p. 390), ‘affirming’ (p. 390), ‘not...burdensome’ (p. 390), ‘appreciative’ (p. 390), ‘affectionate’ (p. 392), ‘loving and trusting’ (p. 392), ‘sensitivity’ (p. 393), ‘closeness’ (p. 394), ‘reciprocity’ (p. 394), ‘life’s little pleasures’ (p. 394), ‘searching for the positives’ (p. 394), ‘joy’ (p. 395),

‘intimate’ (p. 399), ‘pro-active’ (p. 402), ‘involvement’ (p. 404), ‘positive’ (p. 406)

Robinson et al. (2005) is the only paper that acknowledges the idea of positioning and recognises the possibility of the participants’ voices only being positioned voices, due to the possible impact of wanting to be seen in a particular manner.

Participant Voice Representation

While the voice of the researcher is the voice of narrator, the polyphonic nature of narratives would suggest that they are not the only voices to be heard. This is particularly relevant given the recent interest in what happens to relationships in dementia from a qualitative perspective; and given the particular aim of giving voice to the PWD and the couple.

Couple voice

The notion of the ‘couple voice’, a voice that represents the couple rather than the individual voices of each partner is found in four of the five papers. However it is clear that there are different ideas of what represents the couple voice. In Robinson et al. (2005) the couple voice is represented by the separate voices of each spouse, rather than focusing on the interaction and dialogue between the couple. However there are problems with how this voice is represented, for example the process of acceptance is voiced by the PWD, while the process of adjustment is voiced by the spouse. This implies that the proposed dual-process is only ‘dual’ by virtue of each spouse experiencing their own singular process and may therefore not accurately represent the couple voice.

Daniels et al. (2007) claims to represent a joint construction of the couple's story, however the 'couple voice' is only directly heard twice, once in theme 1, and then again in theme 3, with the couple voice predominantly represented by the spouse without dementia. Similarly the couple voice is only heard once in Hellstrom et al. (2007) and is represented by a short extract of dialogue involving both partners.

In Molyneaux et al. (2011), the couple voice is represented by extracts of dialogue between the couples. Of the five couples interviewed, three of them (60%) were represented by husbands with AD and caring wives. The voice of these three couples represents approximately 68 percent of the occasions that the couple voice is heard in the paper. Each couple is heard more or less equally, with the exception of one couple (a wife with Alzheimer's disease and caring husband) who were only represented twice, one of which was a paraphrase by the researchers. The predominance of the wife carer dyad over the voice of the husband carer dyad (32 percent of occasions) could reflect a bias of representing traditional ideas of caring roles of women, and is assumed to represent the voice of the researchers or larger social contexts.

Well spouse bias

The voice of the well spouse was represented more frequently than the PWD in three of the five papers: In Svanstrom and Dahlberg (2004), the well spouse voice is represented by 75 percent of the quotes while in Hellstrom et al. (2007), the well spouse voice is represented by 63 percent of the quotes. In Daniels et al. (2007), the well spouse voice represents the fourth theme (experiences with Alzheimer's Disease) which would intuitively be the place where the PWD's voice should feature quite largely, however this is not the case.

Equal representation

The separate voices of the PWD and well spouse were only represented relatively equally in two papers (Robinson et al., 2005; Daniels et al., 2007). However, even in these papers there were some issues concerning representation. In Robinson et al. (2005) there were variations within the themes. The voice of the PWD is primarily heard in the first higher order theme and the well spouse voice being primarily heard in the second higher order theme (Appendix 2). Similarly in Daniels et al. (2007), the PWD voice is heard in the second and third themes, but the first and fourth themes are mainly represented by the well spouse (Appendix 3).

Absent voice

In two papers, the participant's voice is noticeably absent at times. There is an absence of participant voice in subtheme 6 in Robinson et al. (2005) and in phase 3 in Hellstrom et al. (2007). As the participants' voices are missing it is assumed that it is the voice of the researchers that is being heard.

Context

According to Riessman (2008, p. 105) context could refer to influences such as researchers' influences, settings and social circumstances. As these contextual influences are typically taken for granted by researchers and the readers, their existence and influence is not always apparent (ibid.).

Researchers' Influences

The voice and position of the researchers may be influenced by a number of contextual factors. Some examples could include their chosen occupation, theoretical and methodological/epistemological positions.

Occupational Influences

The researchers' training and occupation will clearly have an impact on the lens by which they analyse and interpret data. Possible influences can be seen in various papers: For example, the authors in Svanstrom and Dahlberg (2004) are both registered nurses, while the primary author in Daniels et al. (2007) is a medical doctor which could account for the medical influences seen in these two papers. Similarly the authors of the Robinson et al. (2005) and Molyneaux et al. (2011) are all psychologists which could give rise to narratives that focus on psychological processes, identity, relationships and ideas about aging. Exceptions to this can be found in Hellstrom et al. (2007) where the authors are all from nursing backgrounds yet provide a paper based on systemic psychological ideas, where other contextual factors may have impacted on the psychological focus from researchers with nursing backgrounds.

Theoretical Influences

In Svanstrom and Dahlberg (2004), the theoretical underpinning of World Life theory was the basis of the methodology of 'reflective lifestory research' used and it gave rise to findings with medical and morality based sentiments. In addition Dahlberg is self-cited five times in the paper; clearly a principal "voice". The systemic influences in Robinson et al. (2005) and Hellstrom et al. (2007), have given bias towards having a relationship-centred focus, viewing spouses-in-context and also a focus on process. While Molyneaux et al. (2011) does not

identify a particular theoretical perspective, the systemic influences are clear in their relationship-centred focus when they advocate for ‘narrative and family therapy approaches’ (p. 17) and view ‘relationships as jointly constructed’ (p. 18). In Daniels et al. (2007) similar theoretical influences are seen in the use of their narrative methodology which positioned the researchers as narrators of the couple’s story. Viewing the research from a narrative perspective gave rise to the focus of joint construction of the couples story, gave voice to a positive perspective and to the position on dementia and relationships. The journey and continuity narratives also seem to intuitively reflect narrative methodologies and narrative structures which highlight temporality, development and movement.

Methodology / Epistemology

The research methodology and epistemological stance may have an influence on the embedded narratives. For example, Svanstrom and Dahlberg (2004) had a phenomenological position that sought to find a fundamentally pure experience or an “essence” (p. 674), which could account for how they have understood and described “the essence of living with dementia” (p. 677) as being characterised by heteronomy and loss. In Robinson et al. (2005) their phenomenological position, which focuses on the processes by which individuals make meaning by being in relation, may have influenced the embedded narratives that focused on processes.

The influence of the possible dynamic relationship between epistemology and theoretical position can be seen in both Robinson et al. (2005) and Daniels et al. (2007). For example, in Robinson et al. (2005), the phenomenological position focusing on process coincided with the process orientation of the systemic theoretical position. In Daniels et al. (2007) the social constructionist perspective and the narrative theoretical position both lent themselves to the

paper's focus on the co-creation of narrative/stories which reflect couples-in-context and as active agents in the creation of meaning. The choice of epistemology and theoretical position and their links may be taken for granted, yet may impact the narratives that are embedded within papers. Furthermore for Daniels et al. (2007) their idea of social constructionism is based on the view that beliefs about everyday concepts (such as marriage) are generated and preserved by studying the social processes in society and thus may also provide an opportunity to uncover embedded narratives that arise from such social processes and the values held within specific populations as represented in that paper. Both Hellstrom et al. (2007) and Molyneaux et al. (2011) have epistemological positions based on 'constructivist' ideas which may account for the focus on the shared constructions and shared experiences of how people make sense of their experiences and thus on the possible embedded narratives. However, they each had different ideas behind their constructivist frameworks. For example, Hellstrom et al. (2007) focused on how meaning is co-constructed through the existence of 'multiple social realities' (p. 387) and exploring social processes over time (for example, caring and the impact of dementia over time), whereas Molyneaux et al. (2011) focused on the 'conversational interactions between spouses' (p. 5) as a means to focus on how couples co-constructed their account of couplehood (such as seen in the provision of extensive couple dialogue and representation of couple voice in this paper).

Settings and Social Circumstances

Institutional Settings

Institutional settings and contexts may refer to the culture of the organisations and departments that researchers are affiliated with, the sites from which research participants are recruited and the journals in which research is published. These are just a few of the types of institutional

contexts that could be present. The influence of these can be seen in Daniels et al. (2007) where one of the authors is a doctor in general internal medicine department, while the other two work in a Child Development and Family Relations department. This could represent the polyphonic nature of narratives and could have given rise to narratives reflecting the voices of the researchers' affiliated organisations. Similar institutional influences can be found in Robinson et al. (2005) where the research participants were recruited from a psychiatry-led memory assessment clinic in the NHS. This may account for the medical narratives found in this paper, despite the researchers all being psychologists.

Publication Journal

Each journal has its own particular aims and goals and thus has a particular position and voice regarding the phenomenon they are concerned with. The process of publishing may entail a number of edits to ensure that the article is congruent with the aims of the journal. As the process of editing could be seen as a form of contextual filtering, the research reported and presented in the journals broadly fits and reflects the position of the journal and their targeted positioned audience. As such the journal in which research is published may provide important contextual influences on how and what research findings are reported. Table 4 shows how the aims and goals of particular journals may provide important lenses or influences when interpreting possible embedded narratives.

Table 4. Publication journal description as context

The Journal	Description of Journal	Article	Possible Influences
Western Journal of Nursing Research (Sage)	This journal is “devoted to the dissemination of research studies...all directed to a general nursing audience.” (Sage, 2012a)	Svanstrom & Dahlberg (2004)	<ul style="list-style-type: none"> • Nursing / medical • Pathology
Aging & Mental Health (Routledge)	This journal covers the “biological, psychological and social aspects of aging...it encourages an integrated approach between the various bio-psychosocial processes and etiological factors associated with psychological changes in the elderly.” (Taylor & Francis Online, 2012)	Robinson et al. (2005)	<ul style="list-style-type: none"> • Biological / Medical • Pathology • Psychological • Social • Aetiological • Processes
Families, Systems & Health (American Psychological Association)	This journal is a “multi-disciplinary journal that publishes clinical research, training and theoretical contributions in the area of families and health.” (American Psychological Association, 2012)	Daniels et al. (2007)	<ul style="list-style-type: none"> • Family/Relationship-centred • Systemic/ Narrative • Theoretical approaches • Systems and Processes • Medical • Psychological
Dementia (Sage)	This journal “acts as a major forum for the social research of direct relevance to improving the quality of life and quality of care for people with dementia and their families.” (Sage, 2012b)	Hellstrom et al. (2007) Molyneaux et al. (2011)	<ul style="list-style-type: none"> • Social • Psychological • Caring • Positive positions

Geographical Location

Riessman (2008, p. 105) proposes that narratives are social artifacts that convey meaning about society and culture. Geographical locations may give clues to underlying socio-politico-cultural values and ideas that may be specific to particular areas and may influence the possible embedded narratives. Research conducted or reported in different geographical areas can thus not be assumed to have the same contextual influences.

The Svanstrom and Dahlberg (2004) and the Hellstrom et al. (2007) research projects were both conducted in Sweden yet both had different positions on the experience of dementia. It is unlikely that the social cultural context of Sweden would have changed dramatically in the three years between the two papers being published and thus it could point to other contextual factors embedded beyond plain view. For example, both papers valued autonomy, which seems to stand in juxtaposition to the socio-cultural-political contexts of Sweden which are based more around social democratic ideas rather than values which assert individuality and autonomy generally found in capitalist countries (Davies & Scase, 1985). Clearly these papers are position statements about dementia and relationships, and may be influenced by cultural values implicit to the locations of the publishing journal rather than those inherent to Sweden per se.

Traditional Values

All the papers only interviewed married heterosexual couples and may highlight 'structures of inequality and power' (Riessman, 2008, p. 115). The geographical locations may give clues to such structures. For example, in Daniels et al. (2007) the conservative and traditional values of

marital relationships and gender roles may be linked with the religious and conservative values that are generally favoured by people in North Carolina and parts of Nebraska. Research by Vazsonyi & Jenkins (2010) highlight the conservative and religious nature of values from this area. Similarly in Molyneaux et al. (2011) such traditional views may be a reflection of the social context of Liverpool, which is a relatively poor and largely working class area where life may embody quite traditional values.

However these structures may reflect the widely prevalent traditional views of male/female, husband/wife and homosexuality/heterosexuality that are insidiously pervasive in society. For example, in Hellstrom et al. (2007) there is the underlying assumption that men do not typically engage in domestic routines or chores (p. 400). Similar influences can be seen in Molyneaux et al. (2011). For example, the use of words such as ‘typical’ (p. 7) are used to discuss spousal roles and ideas about ‘masculinity’ (p. 7) and ‘femininity’ (p. 7). Other influences include discussions around ‘traditional well-defined gender boundaries’ (p. 7), and ‘typical actions and interactions of men and women’ (p. 7). Furthermore the experience of the only unmarried couple in this study was characterised by ‘disagreement’ (p. 10), ‘discontinuity’ (p. 11) and ‘frustration’ (p. 14). Clearly words with negative connotations, perhaps highlighting the underlying bias for traditional values and roles.

Time

Riesmann (2008, p. 7) highlights the temporal development of narratives. Research and narratives are constructed within particular time contexts, and act as artifacts or ‘truths’ of a particular time. While research proposes to provide new and objective findings, the development of ideas and narratives occurs over time. For example, the idea of /nurturative

relational context' and 'couplehood' (Hellstrom et al., 2005a) developed from Kitwood's (1997) idea of 'personhood'. The idea of couplehood (2005a) became the focus for the Hellstrom et al. (2007) paper, which subsequently was the basis of the Molyneaux et al. (2011) paper. Hellstrom et al. (2005a, 2005b, 2007) is influenced by the work of Keady (1999) and Keady and Nolan (2003) on the dynamics of 'working together'. It could thus also be possible that Molyneaux et al. (2011) is subsequently indirectly influenced by these works through their reliance on the Hellstrom et al. (2007) paper idea of 'couplehood'

The development of ideas and narratives over time can be seen in the transition from the deficit and stress-burden models and medical narratives to research that is more positive and relationship-centred. For example, the transition from heteronomy (Svanstrom & Dahlberg, 2004) and loss (Svanstrom & Dahlberg, 2004; Robinson et al., 2005) to choice, autonomy and continuity (Daniels et al., 2007; Hellstrom et al., 2007; & Molyneaux et al., 2011).

Other examples of the development of narratives can be seen in how the Hellstrom et al. (2007) and Molyneaux et al. (2011) papers provide a positive position towards caring and are not characterised by traditional ideas of burden. Robinson et al. (2005) also develop the traditional loss narratives by providing a systemic and psychological focus rather than a focus on deficits.

The Interpreted Narratives

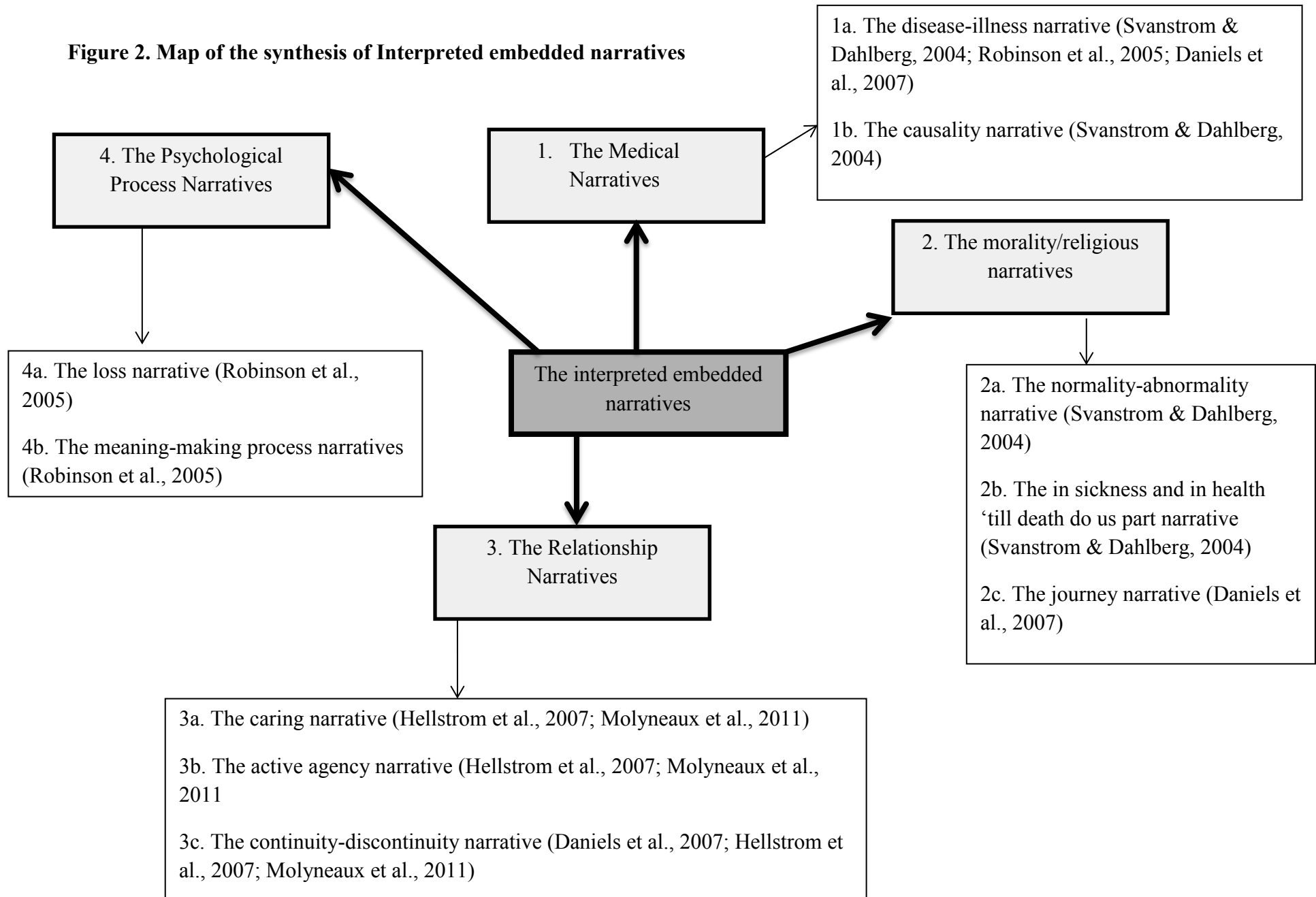
A number of narratives can be interpreted within and across these five papers, from a critical reading of voice, linguistic features and context. Different contexts may be apparent in different papers. Voice, position and context will be commented upon where these were apparent; otherwise it is the researchers' voices which narrate their findings in their papers.

Table 5 shows narratives per paper while Figure 2, show the synthesis of interpreted narratives.

Table 5. Embedded narratives per paper

Paper	Interpreted narratives
Svanstrom & Dahlberg (2004)	The disease illness-narrative The causality narrative The normality-abnormality narrative The in sickness and health 'til death do us part narrative
Robinson et al. (2005)	The disease-illness narrative The meaning-making process narrative The loss narrative
Daniels et al. (2007)	The disease-illness narrative The continuity-discontinuity narrative The journey narrative
Hellstrom et al. (2007)	The caring narrative The active agency narrative The continuity-discontinuity narrative
Molyneaux et al. (2011)	The caring narrative The active agency narrative The continuity-discontinuity narrative

Figure 2. Map of the synthesis of Interpreted embedded narratives



1. The Medical Narratives

This narrative in its broadest sense relates to the role of bio-medical approaches that deal with issues relating to medical issues, illness and symptoms. This overarching medical narrative is one that is commonplace in health care and society in general (Riessman, 2003, 2008). Traditionally, research on dementia has been positioned within a bio-medical approach (Clare, 2002; Kitwood, 1997; Phinney, 1998), this influence is seen throughout all the papers in the prevalence of bio-medical citations in the papers. While each paper cites bio-medical references, not all papers appear to have an embedded medical narrative. There are two sub-narratives, specifically the disease-illness narrative and the causality narrative.

1a. The disease-illness narrative

This narrative is the prevailing paradigm in Western Cultures and is centred on ideas of disease and illness (Riessman, 2003, 2008). It can be found in Svanstrom and Dahlberg (2004), Robinson et al., (2005) and Daniels et al. (2007).

Linguistic Features

In Svanstrom and Dahlberg (2004), the disease-illness narratives can be shown through the use of the word 'heteronomous' (p. 671), which is derived from bio-sciences to describe 'growth, development or specialisation' (Concise Oxford English Dictionary, 2011, p. 668). Furthermore the repetition of the word 'illness' (18 occasions), 'healthy' (33 occasions) and use of words 'disease' (p. 673) and 'sick' (p. 672) sets the scene for an underlying narrative centred around illness. They set the scene for relationships that are defined by symptomatology that renders the couples powerless. Additionally, the use of 'healthy' (p. 673) to distinguish between spouses

suggests an underlying bio-medical perspective specifically around disease and a bias towards the voice of the healthy spouse. The terms ‘healthy spouse(s)’ and ‘healthy partner’ are used 28 and 5 occasions respectively.

Similar bio-medical influences can be seen in Robinson et al. (2005) and Daniels et al. (2007)

(Box 2):

Box 2: Language indicative of a disease-illness perspective

Robinson et al. (2005):

‘treatment’ (p. 337), ‘diagnosis and prognosis’ (p. 337), ‘detection and diagnosis’ (p. 337), ‘disability’ (p. 338), ‘failure’ (p. 338), ‘impairment’ (p. 338), “onset of dementia” (p. 338), ‘prevalence’ (p. 338), ‘healthy’ (p. 339), ‘the insidious nature of the illness’ (p. 339), ‘illness’ (p. 340), “memory problems” (p. 341), and ‘guidelines and protocols’ (p. 345)

Daniel’s et al. (2007):

‘disease’ (p. 162), ‘symptoms of AD’ (pp. 162, 164), ‘caregiver and patient’ (p. 163), ‘the progressive, terminal disease’ (p. 163), ‘degenerative illness’ (p. 168), and ‘the course of the disease’ (p. 175), ‘therapy and/or forms of treatment’ (p. 163)

Context

It is difficult to escape a biomedical perspective in dementia research as dementia is frequently conceptualised as an illness. As seen in the medically oriented words such as ‘illness’, ‘disease’, ‘symptoms’, ‘diagnosis’ and ‘treatment’ that are used to describe dementia in the fact sheet from the Alzheimer’s Society (2011). This prevailing paradigm has a clear influence on how dementia has been, and is being written about. However there are other contextual variables found within the papers. For example, the authors’ professional backgrounds may influence the adoption of this perspective e.g. Svanstrom and Dahlberg (2004) are both registered nurses, with the former completing a doctorate in Health Sciences. Similarly in Daniels et al. (2007), Daniels is a doctor

who works in the department of general internal medicine. While all the authors in Robinson et al. (2005) are psychologists, the research participants were recruited from psychiatry-led clinics in the NHS. Other medical influences could have stemmed from contexts provided by the publishing journals. For example, Svanstrom and Dahlberg (2004) was published in a nursing journal, while the Robinson et al. (2005) and Daniels et al. (2007) were published in journals which both had a focus on biology and health respectively.

1b. The causality narrative

This narrative highlights the cause and effect relationship between dementia and the consequences for the PWD and couple. The implication of this narrative in Svanstrom and Dahlberg (2004) is that dementia causes a ‘heteronomous and lost experience’ (p. 671) for couples. This narrative is closely linked with the disease-illness narrative as the cause in this case is dementia.

Linguistic Features

The assumption that dementia, ‘an illness’ (pp. 671, 672, 677, 681, 682, 683, 684), which ‘has no cure’ (p. 671), is a ‘problem’ (p. 671) and ‘causes’ (pp. 671, 672) various effects for both spouses can be found throughout the paper. This sense of causality is further sustained in the use of language throughout e.g. ‘causes problems’ (p. 671), which leads to ‘difficulty’ (p. 672), ‘the consequence is’ (p. 677), and a ‘feeling of discomfort aggravates their existence’ (p. 677).

Context

The sense of causality in this paper is related to the bio-medical model of disease and symptoms causing the experience of illness. Causality is also a common philosophical foundation/context

for scientific disciplines such as medicine and biology and the social sciences such as psychology (Pearl, 2009). As such the presence of a disease-illness narrative may predicate the existence of the causality narrative. The aetiological focus of the journal in which the research was published may have contributed to the development of the cause-effect narrative in Robinson et al. (2005).

2. The Morality Narratives

These narratives speak to ideas of morality i.e. ‘principles concerning the distinction between right and wrong or good and bad’ (Concise Oxford English Dictionary, 2011, p. 929). This overarching narrative is found in two papers and can be further categorised into three sub-narratives, specifically the ‘normality-abnormality narrative’, the ‘in sickness and in health ‘till death do us part narrative’ and the ‘journey narrative’.

2a. The normality-abnormality narrative

This narrative can be found in Svanstrom and Dahlberg (2004). As an extension of the polarisation of moral ideas of right/wrong and good/bad, this narrative is based on distinctions between healthy/unhealthy, natural/unnatural and normal/abnormal and problem/solution when thinking about dementia as a disease. This narrative seems to suggest that health is considered to be the normal state of being and that illness is not a natural or acceptable state of being. The narrative thread and position running through this narrative relates to the idea that the experience of dementia is heteronomous from what is considered natural or normal.

Linguistic Features

Language plays an important part in creating the sense of what is considered natural or normal in Svanstrom and Dahlberg (2004). Furthermore the ideas of what is natural are contrasted to ideas that are not natural and problematic, for example (Box 3):

Box 3: Language indicative of ideas of normality/abnormality

- ‘during dialogue, people *normally* confirm and are *corrected*...’ (p. 672)
- ‘...for what was previously *natural* for her to do.’ (p. 678)
- ‘...they do not feel at home in places where it was previously *natural* for them to be...’ (p. 682)
- ‘...losing their natural roles...’ (p. 684).
- ‘neither the spouse with dementia nor their healthy partner can see a *solution* to the *problem*...’ (p. 683)
- ‘Dementia is a significant public health *problem*’ (p. 671)
- ‘The illness alters the affected person’s ability to communicate, resulting in *difficulties* ...’ (p. 671)
- ‘Spouse and relatives have *problems*...’ (p. 672)’
- “They have *problems* perceiving and thus feeling that their life is coherent.” (p. 684)

According to the Concise Oxford English Dictionary (2011, p. 954) the word ‘natural’ is defined as something being ‘normal’ and relating to ‘law and justice’ that is based on ‘innate moral sense’. The adjective ‘normal’ refers to something that is ‘usual, typical, or expected’ and stems from the Latin ‘norma’ (norm), which refers to a ‘required or acceptable standard’ in mathematics and science (Concise Oxford English Dictionary, pp. 975-976). It is clear that the choice of words has a clear impact on the creation of this narrative. The use of words such as ‘natural’, ‘normally’ and ‘coherent’ to describe a healthy state, in comparison to words such as ‘problem’ and ‘difficulties’ that denote some form of dis-ease from the norm, may further

reinforce the idea of dementia as being abnormal. It is such linguistic techniques like the rhetoric effect of using words with moral etymologies and words with accessible polar or antonym pairs such as natural/unnatural and normal/abnormal that may persuade the reader to agree with the position that couples affected by dementia are living a 'heteronomous and lost existence' (p 671).

Context

The context relates to the researchers' theoretical position of Life World Theory. The researcher's do not explain what this theory entails. However work by others would indicate that the theory has strong ties with biology, religion and moral reasoning (Endres, 1996). This is further supported by the methodology of 'reflective lifeworld research' appearing to have been created by one of the authors. Clearly the theoretical position and development of the researchers' own previous ideas lay as the context for this narrative. The use of language may be a product of a nursing and medical context of the researchers and journal where there may be clear ideas of what normal and natural health is, and where ill health is viewed as problematic.

2b. In sickness and in health 'till death do us part narrative

Morality is one of the fundamental tenets of religious beliefs as illustrated through stories that represent moral lessons as in the Bible. This narrative gives rise to questions of moral reasoning over choice, and personal freedom and independence within spousal relationships. It is linked with the 'right way' of doing things, and hinges on the religious and social norms and traditions (contextual institutions) such as marriage, which often have a religious and moral foundation. This narrative is embedded in Svansson and Dahlberg (2004). The position behind this narrative

seems to suggest that personal choice and autonomy is subjugated by the unconditional moral duty and responsibility that spouses must have towards each other.

Linguistic Features

As seen in Box 4, the sense of moral duty and responsibility is created through the use of language in the paper, for example:

Box 4: Language indicating a sense of duty and responsibility

- ‘The healthy spouse has a *moral responsibility* for the person with dementia and is unable to be independent.’ (p. 677)
- ‘Although taking *responsibility* in terms of being a *matrimonial duty* in the present study, oftentimes this appeared to be the case.’ (p. 684)

Furthermore, the use of words such as ‘bound’ (p. 678) and ‘tied’ (p. 678) when referring to the increasing responsibility of the well spouse, is reminiscent of ancient marital hand-fasting ceremonies where spouses are spiritually and literally bound to each other (Neasham, 2003). The use of ‘bound’ and ‘tied’ could also play a secondary rhetoric function of epitomising the sense of a ‘lack of freedom’ (p. 678), being ‘powerless’ (p. 678) or having no ‘real influence’ (p. 678) and how spouses are bound by a sense of duty and responsibility rather than active choice and free will; thereby giving the sense of possible entrapment in a marriage through moral responsibility and matrimonial duty rather than autonomous choice.

Context

The link between the researchers' theoretical position and religious and moral reasoning act as the context and lens through which the researchers voice the implicit and explicit values and traditions of the institution of marriage.

2c. The journey narrative

This narrative can be found in Daniels et al. (2007) and speaks to the metaphoric idea that couples are on a journey, and that the journey is a unique experience for each couple. However it also speaks to larger social processes and shared stories about marriage as a journey and the experience of dementia for couples as a journey.

Linguistic Features

It could be interpreted that the use on words such as 'commitment' and phrases such as 'lifelong commitment' may be underpinned by the traditional religious and moral ideals of marriage vows and the spiritual connection and journey that spouses commit themselves through marriage. The words 'commitment' (and derivatives) are used on 22 occasions. The notion of spiritual connection and journey are not new to dementia research (Smith, 2001). As shown in Box 5, the use of language with religious overtones may in part reflect the conservative values favoured by many people living in that culture:

Box 5: Language with possible religious overtones

'devoted' (p. 166), 'The intimate bond between a husband and a wife' (p. 162), 'couple's devotion' (p. 169), 'harmonious' (p. 173), 'hope' (p. 175) and 'embodied' (p. 177)

Furthermore there is an idea that the couple's relationship is a journey itself; for example, there is reference to the couple's 'history' (p. 168), a word denoting a continuous and chronological story of past events suggests the couple have already been on a journey; whilst the 'preparation for the future' (p. 169) is suggesting the continuation of the journey/story. This is further instilled through repetition of the length of the marriage on five occasions. There are 14 references to 'lifelong', which may be indicative of a past and a future to come, while also possibly reflecting the traditional religious values (associated with marriage as a lifetime commitment and journey) that are commonly held by people from that geographic area.

Context

A number of contexts may be at interplay with each other as a means to facilitate the interpretation of the journey narrative e.g. pre-existing narratives, the methodological position of the researchers and socio-cultural values reflective of a specific geographic location. The journey narrative is not a new narrative to older adults and dementia and the idea fits well with the progressive nature of dementia, likening the couple's story to the move through the progressive stages of dementia. This is mirrored in the researcher's comments such as 'this sub category encompassed specific changes in roles that took place...following the progression of the Alzheimer's disease' (p. 171).

The methodological narrative lens adopted by the researchers may act as the context which could contribute to the creation of the journey narrative. For example, the researchers approached the interviews as a means to co-create the couples 'unique story'

(p. 164). Furthermore, the idea of narrative is predicated on the ideas of a beginning, middle and an end and the plot/story development through ‘important moments’ (p. 164). The impact of the context is given further credence by two of the authors being located within a child development and family relations department; as such these authors could presumably have a perspective that is characterised by people and relationships developmentally over time, thus again suggestive of a person or couple progressing through phases. The geographic context where the research was conducted may play a role in the researchers’ and participants’ position and views of marriage, family values and the roles of men and women.

3. The Relationship Narratives

3a. The caring narrative

While a caring narrative is not new to dementia research, this version highlights caring as being an extension of an existing spousal role and not a transition to an entirely new role without spousal attachments. This provides a more positive position on the relational changes and focuses on equality and reciprocity rather than the deficit and stress-burden caring models traditionally seen in dementia research. This narrative is seen in Hellstrom et al. (2007) and Molyneaux et al. (2011).

Linguistic Features

In Hellstrom et al. (2007), the word ‘caring’ is mentioned on 25 occasions, whereas the couples themselves do not mention the word ‘carer’ or ‘caring’ in their quotations; while in Molyneaux et al. (2011), the words ‘caring’ and ‘carer’ are used on 14 and 13 occasions respectively, and are voiced by both the researchers and participants.

In Hellstrom et al. (2007), caring is referred to as ‘dimensions’ (p. 386) and ‘elements’ (p. 405) of caring, where the ‘caring spouse(s)’ engage in ‘caring activities’ (p. 394) and ‘caring arrangements’ (p. 406). Similarly in Molyneaux et al. (2011), caring is positioned as the active ways that couples ‘co-construct’ (p. 8) their changing relationship based on relationship history. The focal position of this narrative in both papers is that caring is an extension of spousal relationships and roles rather than a marital duty or responsibility, and that the developing caring relationship still retains spousal qualities. For example in Hellstrom et al. (2007), spouses and the relationship are defined by both caring spousal roles (indicating spousal identity) such as a ‘caring wife’ (p. 394), ‘wife carers’ (p. 405), and ‘husband carers’ (p. 405). In Molyneaux et al. (2007), the theme of ‘technically a carer’ identifies that, although the relationship may change and incorporate caring, the role identity of husband/wife does not change entirely to that of carer. This is further supported by how couples retained a sense of couple identity and spousal roles by how they actively ‘resisted’ (p. 12) or ‘rejected’ (p. 13) being the carer or cared for.

Context

Despite aiming to provide a new perspective/position on the impact of dementia on relationships, both papers still contribute to the caring narrative. They both however position themselves against the traditional notions of caring relationships defined by stress-burden models, by not characterising the changing spousal relationship as ‘burdensome’ (Hellstrom et al., 2007, p. 390) or as a ‘burden’ (Molyneaux et al., 2011, p. 2). The influence of the systemic and relational focus is evident throughout the focus on ‘couplehood’. Furthermore the development of ideas/narratives can be seen in the progression of Kitwood’s (1997) idea of ‘personhood’ to

Hellstrom et al.'s. (2005a) idea of a 'nurturative relational context' is the basis for their idea of 'couplehood' in 2007, which is the basis for the research by Molyneaux et al. (2011). The journals' focus on reflecting quality of caring, family relationships and positive accounts may have contributed to the relational focus on caring and the positive position. The primary and secondary authors in the Hellstrom et al. (2007) paper both have interests in caring and family relationships (Linköping University, 2012; & Sheffield University, 2012) which could account for the relational focus and caring narrative present in Hellstrom et al. (2007).

3b. The active agency narrative

This narrative portrays spouses as actively working to maintain connection and individual and couple identity. The focus is not on the losses experienced by the PWD and the couple, but on the active nature in which well spouses compensate for these changes. The focus on agency detracts away from the more negative experiences and thus highlights the active role that couples assume as a means to maintaining relational continuity despite dementia. This narrative is embedded in Hellstrom et al. (2007) and Molyneaux et al. (2011).

Linguistic Features

In both papers the researchers' voice and position promotes that couples must be actively engaged in goal-oriented and purposeful behaviors within their relationships. Through the use of language, value is placed on active participation, activity, and personal and couple agency. In Hellstrom et al. (2007), the word 'active' (and derivatives) are used on 22 occasions. The word 'strategy' denotes choice, activity, and goal orientation as opposed to passivity, and is used on 10 occasions. The researchers actively position couples as being active. Similarly in Molyneaux et

al. (2011), the use of ‘motivated’ (p. 10), ‘strategy’ (pp. 8, 11), ‘active’ (pp. 2, 8, 10, 16, 18), ‘promote’ (pp. 2, 3, 12, 17) and ‘promoted’ (pp. 10, 11, 16) highlight the active nature of doing and are positive words with positive connotations. Furthermore examples of verbs and phrases suggestive of action and agency are apparent in both papers (Box 6):

Box 6: Language conveying sense of action and agency

Hellstrom et al. (2007):

- ‘adopt’ (p. 383), ‘adopted’ (p. 398), ‘strive’ (p. 383), ‘operated’ (p. 383), ‘seek/seeking’ (pp. 83, 395), ‘dynamic(s)’ (pp. 384, 386, 391, 407), ‘work’, ‘working’ and ‘worked’ (pp. 386, 387, 389, 392, 393), ‘create’/ ‘creating’ (pp. 383, 387, 390, 402, 404), ‘distancing’ (p. 396), ‘coping’ (p. 396), ‘employed’ (p. 396), ‘effort(s)’ (pp. 393, 393, 395, 398, 404, 405), ‘deliberate’ (pp. 398, 405), ‘compromise’ (p. 392), ‘respond/response’ (pp. 393), ‘hiding’ (p. 394), ‘demonstrate/demonstrating’ (pp. 393, 394), ‘agency’ (p. 399), ‘caring’ (p. 399), ‘contribute’ (pp. 399, 401), ‘contribution’ (p. 400), ‘pursue’ (p. 399), ‘negotiated’ (p. 399), ‘ensuring’ (p. 400), ‘celebrate’ (p. 400), ‘playing’ (p. 400), ‘learn’ (p. 401), ‘help’ (p. 401), ‘protect’ (p. 402), ‘engage in’ (pp. 394, 398), ‘voicing their appreciation’ (p. 394), ‘doing things together’ (p. 394), ‘making the best of things’ (p. 394), ‘searching for the positives’ (p. 394), ‘conscious decision’ (p. 396), ‘keep the peace’ (p. 398), ‘took over’ (p. 402), ‘Invested considerable effort ingenuity’ (p. 390), ‘considerable energy and effort being expended’ (p. 404), and the taking of risks by the couple (pp. 400, 401, 405).

Molyneaux et al. (2011):

- ‘participation’ (p. 2), ‘engaging’ (p. 2), ‘activities’ (p. 2), ‘sustaining’ (p. 3), ‘involvement’ (p. 3), ‘contributions’ (p. 5), ‘accomplish’ (p. 6), ‘achieve’ (p. 6), ‘adjustment’ (p. 6), ‘endeavoured’ (p. 8), ‘rushed’ (p. 9), ‘attempts’ (p. 10), ‘minimized’ (p. 10), ‘viewed’ (p. 11), ‘reminiscing’ (p. 12), ‘reflected’ (p. 12), ‘persevere’ (p. 12), ‘normalized’ (p. 15), ‘testing’ (p. 16), ‘strive’ (p. 17)

Language that portrays goal-orientation, purposeful behavior, activity and agency in Hellstrom et al. (2007) and Molyneaux et al. (2011) is juxtaposed with the language used in Svanstrom and Dahlberg (2004) which portrays passivity and helplessness. It is also juxtaposed with commonly perceived stereotypes of the gradual decline in activity and participation in the aged.

Context

The focus on ‘couplehood’ as being a progression of Kitwood’s (1997) idea of Personhood is contextually significant. Both papers acknowledge their relationship-centred approaches and thus a possible systemic theoretical context through which the data were interpreted and reported. The context for Molyneaux et al. (2011) could be the Hellstrom et al. (2007) paper thus again highlighting the development of ideas and narratives over time. The idea of ‘choice’ was seen in Daniels et al. (2007) and may have provided a context for both the Hellstrom et al. (2007) and Molyneaux et al. (2011) papers to develop. This narrative positively positions the activity and participation of older couples which may reflect the publishing journals aim of improving the quality of life for people and families. The positive focus may also be a time factor and how previous research and narratives develop, and the recent move away from the deficit and stress-burden models traditionally used in dementia research (Montgomery & Williams, 2001; McGovern, 2011) representing the move away from the idea of the lack of choice presented in the Svanstrom and Dahlberg (2004) paper.

3c. The continuity-discontinuity narrative

This narrative refers to relational continuity and discontinuity. The term continuity refers to how couples respond to relational changes; specifically to whether or not these changes have or have not led to a climactic point where the spouse or relationship is perceived as being radically different. A continuous relationship is one where there are changes, but these have not led to a radical re-appraisal of the relationship or a change in the bonds at the core of the relationship. A discontinuous relationship would be one where the changes have triggered very different feelings

towards the spouse or the relationship. This narrative is embedded in Daniels et al. (2007), Hellstrom et al. (2007) and Molyneaux et al. (2011).

Voice

Each paper has a slightly different idea of continuity which is assumed to reflect the researchers' voices. For Daniels et al. (2007) continuity reflects the 'lifelong commitment' (p. 167) and continued choice to remain together despite dementia. For Hellstrom et al. (2007) continuity is related to the active agency narrative where couples actively and deliberately work at maintaining their 'nurturing relational context' (p. 383). For Molyneaux et al. (2011) the focus is on spousal roles, identity and how couples co-construct meaning. The position of the three papers portraying couples as actively choosing continuity detracts away from the heteronomy proposed by Svanstrom and Dahlberg (2004).

Linguistic Features

The sense of continuity is created through the use of language that denotes movement and time. In Daniels et al. (2007), the repetition and use of words with time connotations such as 'story' (79 occasions) 'lifelong' (15 occasions), 'history' (3 occasions), 'journey' (2 occasions), and 'preparing for the future' (p. 169) highlight temporality. In Hellstrom et al. (2007) and Molyneaux et al. (2011), the use of 'sustained' and 'maintain' speak to the notion of the continuation of their pre-existing relationship. The word 'sustain' (and derivatives) is used on 35 occasions in Hellstrom et al. (2007) and on 3 occasions in Molyneaux et al. (2011). Similarly the word 'maintain' is used on 33 occasions in Hellstrom et al. (2007) and on 21 occasions in Molyneaux et al. (2011).

Each of the three papers positions continuity as being the preferred state. In Daniels et al. (2007), the repetition of the length of marriage 6 times could be a linguistic feature used to highlight the significance of the temporal aspects of the achievement of such a lengthy marriage. In Hellstrom et al. (2007), the positive bias is evident in the focus on maintaining the ‘treasured’ (p. 390) ‘ways of being’ (p. 392) by ‘making the best of things’ (p. 394) and ‘searching for the positives’ (p. 394). In Molyneaux et al. (2011), there is the sense that continuity promotes the ‘normality of their relationship’ (p. 6), suggesting that continuity is the preferred state. Continuity is described in terms of ‘love’, ‘trust’, ‘affection’ and ‘appreciation’ (Hellstrom et al., 2007, p. 393) and ‘affection’, ‘love and tenderness’ and ‘mutual support’ (Molyneaux et al., 2011, p. 8). Such words have more positive attributions than those used to describe discontinuity. Daniels et al. (2007) described the experience of discontinuity as ‘lonely’ (p. 168) and ‘unusual’ (p. 169). For Hellstrom et al. (2007) discontinuity is characterised by language such as ‘passive’, feeling ‘alone’, being ‘less active’ and the transition from a ‘we’ to an ‘I’ (all p. 403). Similarly in Molyneaux et al. (2011) the language used to describe discontinuity includes ‘challenge’ (pp. 6, 7), with ‘consequences’ including ‘frustration and uselessness’, ‘confusion’, ‘anxiety and distress’ and a sense of ‘dependen[ce]’ and unpredictability (all p. 7).

Context

This narrative is influenced by previous research by Wright (1993, 1998), Chesla et al. (1994), Kaplan (2001), Keady (1999), Keady and Nolan (2003) and Hellstrom et al. (2005a, 2005b). The narrative highlights how knowledge/narratives develop over time. For Molyneaux et al. (2011) the focus on ‘couplehood’ relates to identity, which is similar to Hellstrom et al. (2005a, 2007), but is different to the focus of commitment in Daniels et al. (2007) which may be linked to the

journey narrative found embedded in that text. This narrative is a development of various ideas that have been in dementia research for some time. The position on continuity being the preferred state may be influenced by factors such as the publishing journals' positive focus on improving the quality of life for families and the PWD.

4. The Psychological Process Narratives

The focus of these narratives is on the *psychological experience* of dementia. This experience is conceptualised in terms of *processes* such as how couples understand the experience and how they react to the changes. There are two sub-narratives that fall within this category, specifically the loss narrative and the meaning-making process narrative; both which are found in Robinson et al. (2005).

4a. The Loss Narrative

This narrative speaks to the dual process of accepting and adjusting to losses that are experienced in relationships affected by dementia. For example, it encapsulates ideas such as the loss of their 'social identity', 'relationship', 'roles', 'intellectual change', 'previous lifestyle', 'support from friends and family', their 'reactions to loss', the 'grieving' process (all pp. 338-339), 'loss of independence' and 'memory loss' (all p. 342).

Linguistic Features

The word 'loss' (and derivatives) is used on 38 occasions. The psychological influences of how loss is conceptualised can be seen in phrases such as 'psychological responses to loss' (p. 337) and 'psychological reactions' (p. 339, 346). The ideas of loss are clearly positioned within

existing ‘theories’ and ‘concepts’ of loss (p. 339), particularly the ‘dual process models of grief’ (pp. 337, 344), and the ‘dual process models of loss’ (p. 339) and are characterised by words such as ‘adjustment’ and ‘acceptance’ (and derivatives, used on 31 and 13 occasions respectively).

The systemic influences can be seen in that these psychological responses are all ‘process’ based.

Context

The focus on process and the need for loss to be considered with a ‘systemic perspective’ (p. 339) highlight the impact of the researcher’s theoretical position. The researchers’ profession of being psychologists have given particular focus of the paper to the ‘psychological experience of developing dementia’ (p. 338) This narrative also illustrates how traditional ideas of loss in dementia are developing to include ideas that focus on the processes and how couples understand and experience that loss, rather than being burdened by the deficits.

4b. The meaning-making process narrative

This narrative refers to the processes whereby the couple understands their individual and joint experience of dementia. This narrative highlights how meaning-making is active and is socially constructed through their spousal relationships. This meaning-making process is about ‘making sense and adjusting to loss’ (p. 343) and ‘accepting dementia’ (p. 343)

Linguistic Features

The systemic influences and the idea that meaning is a socially constructed process are portrayed through phrases such as ‘the process that occur in relation to others...’ (p. 340), ‘circularity for

couples in the process...’, ‘cyclical process’, ‘negotiation’ (all p. 343), ‘shared sense of identity’ (p. 337) and ‘process of constructing’ (p. 337).

Context

The researchers’ ‘constructivist’ methodology and epistemological position may be a basis for the social construction of meaning, while the focus on process could be underscored by their systemic theoretical position.

Summary

The narratives embedded in the selected papers fall into four overarching categories, specifically the Medical, Morality, Relationship and Psychological Process narratives. A number of sub-narratives were also identified. The review has commented upon the variable contribution of voice, linguistic features and context on the interpretation of embedded narratives. Research is narrated by the researchers; however there are a number of contextual factors that may influence that voice. Some examples may include their theoretical and epistemological positions. Riessman (2008, p. 107) advocates that the idea of voice speaks to how identities are performed and positioned. The polyphonic nature of voice proposes that there may be multiple voices and positions present in a text. For example, the voice of research participants may be voiced through the researcher’s voice. The polyphonic nature of narratives could also account for different narratives being present in the same paper.

A variety of methodological issues complicate the representation of voice: The representation of the voices of the well spouse and PWD is variable, with a bias for the unequal representation of the well spouse. Only two papers showed a relatively equal contribution by both spouses. There

were also occasions where findings in the papers were not supported by the representation of the participants' voices.

Linguistic features and various contexts were shown to impact the embedded narratives. Contexts may refer to different influences that may persuade the narrator and audience to a particular interpretation. This review has shown how narratives build upon existing knowledge and narratives, as opposed to showing something entirely new and unbiased and thus highlights the need for researchers to pay active attention to ideas of voice, linguistic features and context in how they present their research to their targeted audience. It also invites the reader to engage in a critical reading of research findings, as the embedded narratives may reflect more than just the experience of those they claim to represent.

DISCUSSION

Through the analysis of the performance of language, voice and context, the presence of embedded narratives can be interpreted. As has been shown, every paper is polyphonic, has a position, actively uses language and is embedded within a context. This review is no exception. As it is fundamentally impossible to escape our own narratives, there is a need for researchers to reflect upon what they bring to their research and the influences and lenses by which they perceive and interpret their data. A more explicit description of these influences and how they engaged with the data may help contextualise the findings and may better position the reader to receive the findings, being informed of the underlying values and principles.

The differences in socio-cultural-political contexts, language, methodology and theory render papers as single instances that show a truth related to those specific participant's, context and time. We can never assume that research in the same area takes a similar stance in relation to its subjects. Even across qualitative papers, it is clear that claims of co-construction are viewed from slightly different epistemological perspectives. As such researchers could be encouraged to be more aware of, and transparent about their positions, while readers can be invited to actively engage in their reading, noticing their own biases and not simply accepting that all research has similar foundations and is thus comparable. In thinking about the philosophy of science and the illusion of objectivity, research cannot escape the influence of socio-cultural factors and the dominance of the prevailing paradigms.

Furthermore, I propose that context is fundamentally influential in the choice of topic studied, the methodology and theory chosen, and how the findings are presented. As we are bound by our own narratives, each interpretation, although valid, is none-the-less different as each reader is differently influenced by an infinite number of contexts.

At times, the researcher's voices reflected the voices of past research. This is demonstrated in the recurrence of narratives such as the continuity/discontinuity and active-agency; which suggest the temporal development of narrative. The notion that any research is unique is a myth as it is impossible to untangle ourselves from our ways of knowing. Researchers therefore need to question and clarify their motives for positioning themselves as providing something different or new or in allegiance to or opposition to historical works. Perhaps dementia experience needs to be viewed in a more systemic and holistic manner with multiple realities, which encompasses all

perspectives⁵. The biomedical, stress-burden and relationship-centred narratives are all equal stances and provide a more holistic view of the individual, the couple and contexts. To ignore the medical narratives is doing a disservice to understanding the physical and medical changes experienced by the couple. Clearly the medical narratives are inescapable as dementia is a disease. However to privilege the medical narratives, provides a simplistic reduction of the experience and does not capture the intricacies of couples relationships or the many other narratives that have shown to be embedded in research. Furthermore future research could attend to the possibility that couples hold empowering narratives and not necessarily just the stress-burden narratives. Perhaps the narratives of journey and continuity may be helpful in highlighting different aspects at different times in the course of dementia. For example, at diagnosis there may be a justification for a more medical approach, while at others to focus on relationship aspects.

All of the papers positioned themselves as providing a new perspective on relationships that moved away from the biomedical or stress-burden models. However even in cases where the medical narrative was not present, there were still linguistic remnants that hinted of a medical context or a historical medical narrative. It is difficult to remove the medical narrative entirely, but researchers could be enabled and invited to be more conscious about language as it may inadvertently promote a narrative that they do not wish to strengthen. The inclusion of the medical narratives could clearly impact on clinicians' views of how to work with couples, and may miss the interpersonal intricacies relating to the couples presentation as shown by the relationship and psychological process narratives. If the medical narratives are imposed, this could impact the caring and relationship experience for both partners and detract from the

⁵ However in this, I acknowledge my own bias for the systemic which is the basis for this statement and in itself provides the very paradox to multiple realities/perspectives.

researchers' key messages about interpersonal intricacies. However if it is the narrative held by the couple, then its inclusion is understandably warranted.

Similarly the caring narrative seems to be the prevailing way of conceptualising couples' relationships with dementia. I do not dispute that there are caring elements, but by defining it only as caregiving tends to undermine other relationship qualities. The caring narratives present in the papers reviewed were careful to position the view of caring more positively than that of earlier conceptions of the caring relationship in dementia characterised by stress and burden. However this focus on the positive poses some interesting challenges which shall be discussed later. Again, if this is the narrative held by the couple, then it's' inclusion is unquestionably merited.

The PWD's voice is not always well represented, despite the aims and claims of doing so. It was clear that at times the methodological and theoretical approach privileged certain voices while silenced others. For example, methodological issues might privilege the voice of the well spouse such as in Svanstrom and Dahlberg's (2004) paper, or there may be biases created by theoretical frameworks, as in the Robinson et al. (2005) paper where the strong adherence to the systemic framework made the researcher's voice almost indistinguishable from the systemic framework, and thus the findings could have been more a reflection of a theoretical perspective than the couples actual experience.

Similarly the attempts to show the 'couple voice' were fraught with issues of paraphrasing, the use of unattributed quotes and the unequal contribution of each partner's voice as seen in the Daniels et al. (2007) paper. Furthermore, the couple voice sometimes seemed to be represented

by both partners, such as in the Robinson et al. (2005) paper, but tended not to represent the shared story; rather, it seemed to provide narratives from two individuals. Even when the couple voice was represented by extensive extracts of dialogue between couples, such as in the Molyneaux et al. (2011) paper, there appeared to be a bias towards the female being represented in the caring role. This lack of male⁶ carers' voices is also seen in the Robinson et al. (2005) paper. Husband and wife carers may have different experiences of caring or being cared for, particularly thinking about some of the traditional values that are embedded in the papers and which seem to further embed traditional roles of women as carers. As such, future research could address the gaps such that male carers have an opportunity to have an equally represented voice. This will serve to better support not only couples, but also the individual needs of each partner. This bias also highlights the opportunity for researchers and clinicians to be aware of our own embedded ideas about marriage and traditional roles, and where possible to acknowledge how these impact our view of relationships, and how this may be similar to or different from the couples with which we work. It furthermore highlights the significance of presenting the couple's voice with minimal noise from our own values, or implicit social-cultural contexts.

The voices are impacted by some of the embedded narratives as demonstrated in Daniels et al. (2007) - where the husband had a particularly medical perspective. It is also the researcher's voice in all the papers that provide the narration for the embedded narratives, and may reflect their own personal biases and interpretation of larger social processes and contexts; and which may be unconsciously used to gain acceptance with an audience of health professionals.

⁶ This may be that women live longer than their male spouses and that most carers are women.

The influence of previous research and the development of ideas can be seen in the Hellstrom et al. (2007) paper - where the researcher's voice seemed to be influenced by researchers before them. This influence of previous research also served as a positioning tool, where both of these papers positioned themselves in alliance to other positive accounts, while distancing themselves from the more distressing perspective presented by Svanstrom and Dahlberg (2004).

Similarly the notion of choice appeared in Daniels et al.'s (2007) article, and developed through the Hellstrom et al. (2007) and Molyneaux et al. (2011) papers to become a narrative of active-agency. Clearly, the development of ideas and knowledge is predicated on previous knowledge as well as being influenced by contextual factors. Embedded narratives therefore reflect more than the couples experience, but are historical artifacts of previous narratives.

It is evident that linguistic features play an important and active role in the creation of meaning. The use of language can set up the general tone of the paper, as seen in Svanstrom and Dahlberg (2004) and Hellstrom et al. (2007). Use of words are associated with historical and cultural discourses, and contain remnants of embedded narratives. This is evident in Daniels et al. (2007), where language appeared to have origins in religious and conservative ideals commonly favoured by people from a particular geographic area. I propose that researchers may want to pay more attention to the language and linguistic devices that they use.

In all the papers, features such as the use of repetition and frequency of words may have inadvertently set up a sense of privileging particular positions. This invites researchers to be more aware of the language in which they present their findings. Language itself is not only a means to

a voice, but a voice in and of itself, conveying more than simply what is written. However we rarely pay active enough attention to what we read to be aware of this.

The bias to show the positive aspects of relationships rather than the more distressing side of the impact of dementia was evident throughout the review, the exception being that of Svanstrom and Dahlberg's (2004) paper. Majority of the papers positioned themselves in opposition to the distressing view presented by Svanstrom and Dahlberg (2004). There is a sense that couples and the PWD needs to be shown as active, having a sense of agency, and engaging positively in relationships. Positivity is a position statement providing a commentary to our need as humans to firstly aspire to the positive but also to position ourselves in the best possible light. Highlighting the positives, while diminishing the potential distress and more heteronomous experiences, may be an attempt to defend against our own anxieties about dementia and aging. Unfortunately in so doing there is the possibility that the voice of the couple and the PWD may be lost in the positive reframe. Without the forum to openly and freely discuss the more distressing side, services may be doing a disservice to couples who may be struggling either with accepting the diagnosis, or the increasing difficulties that they may experience as dementia progresses.

Continuity in relationships seems to be bound up with the idea of the couple's choice to continue to be involved as in Daniels et al.'s (2007) article, or the strategies that couples employ to maintain a nurturative relational context in Hellstrom et al.'s (2007) paper. It is clear that continuity is a positive and preferred state as compared to discontinuity. If this is the implicit message given to couples, researchers and clinicians may firstly, be inadvertently locating blame for discontinuity within either partner or the couple, and secondly, assuming that relationships that are not continuous may not be rewarding. Perhaps then the culture of blame and the bias of

showing the positives could account for part of the experience of distress and burden within these relationships.

It could be argued that the narratives on dementia and heterosexual couples solely provides narratives on traditional relationships. Although this could arguably be a cohort effect, it could also be linked with implicit and explicit forces of the prevailing social-cultural contexts; which has been evident in the existence of traditional roles of men and women in the narratives presented in this review. More non-traditional couples will emerge in line with shifting socio-cultural attitudes, as such future research may have the opportunity to give voice to the experiences of these couples. While all relationships share certain characteristics, non-traditional relationships may have different layers that may impact the experience of dementia. For example, the accessing of services and the legal rights and benefits afforded to same sex-couples or how services provide services to couples. Of course one must account for the possibility that these voices have not been represented, not only due to the prevailing culture, but out of forced choice or fear for not conforming to the status quo. Which are in effect consequences of the prevailing culture.

The morality narratives provide interesting debate around views on abnormality and normality. It could be that the sense of burden results from pressures derived from the prevailing status quo. For example, the need to have positive continuous relationships may stem from moral ideas of marital responsibility and duty or from religious doctrine. Without acknowledging the existence of such embedded narratives, researchers and clinicians are only viewing part of the picture. The limitations of this review, are by very nature the same that this review has attempted to show. I am bound by my own narratives. This limitation highlights the inescapable nature of our contexts

and that we could be enabled and encouraged to be more transparent about our voice, position and language. This review is limited by the small number of papers reviewed – however conceptually it has aimed to highlight the performance and potential existence of embedded narratives and thus while these may be different in papers that were not included, the concept of active engagement and performance of linguistic features, voice and context remain pertinent.

CONCLUSION

It has been clear from the review that linguistic features have a profound impact on the interpretation and tone of the paper and may bias a reader's interpretation. This review therefore highlights an invitation to critically examine the use of language. It is also evident that narratives embedded in research papers may reflect the prevailing socio-politico contexts, or particular theoretical or methodological positions, rather than just the couple's experience. The issue of voice is relevant to qualitative papers and the claims to be representing the PWD voice and the couple's voice as separate and distinct. It is clear that the degree to which all the voices are represented is affected by many factors. Researchers have a responsibility to be transparent about how they have engaged with their data sets and the potential influences that may have impacted upon the interpretation, while readers are accountable for being more aware of their own biases and actively engaging with research papers.

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APPENDICES

Appendix 1. List of articles found from search

1. Clare & Shakespeare (2004). Negotiating the impact of forgetting. Dimensions of resistance in task-oriented conversations between people with early-stage dementia and their partners.
 2. Svanstrom & Dahlberg (2004). Living with dementia yields a heteronomous and lost existence.
 3. Hellstrom, Nolan, & Lundh (2005a). 'We do things together': A case study of 'couplehood' in dementia.
 4. Hellstrom, Nolan, & Lundh (2005b). Awareness context theory and the dynamics of dementia. Improving understanding using emergent fit.
 5. Robinson, Clare, & Evans (2005). Making sense of dementia and adjusting to loss: Psychological reactions to a diagnosis of dementia in couples.
 6. Daniels, Lamson, & Hodgson (2007). An exploration of the marital relationship and Alzheimer's disease: One couple's story.
 7. Davies & Gregory (2007). Entering the dialogue: Marriage biographies and dementia care.
 8. Hellstrom, Nolan, & Lundh (2007). Sustaining 'couplehood'. Spouses' strategies for living positively with dementia.
 9. Walters, Oyeboode, & Riley (2010). The dynamics of continuity and discontinuity for women caring for a spouse with dementia.
 10. Molyneaux, Butchard, Simpson, & Murray (2011). The co-construction of couplehood in dementia.
 11. Davies (2011). Preserving the "us identity" through marriage commitment while living with early-stage dementia.
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Appendix 2. Representation of voice (Robinson et al., 2005)

Themes	PWD Voice	Spouse voice
First higher order Theme: ‘Not quite the same person, tell me what actually is wrong’		
1. ‘You don’t notice straight away’	Once by a Husband	Not represented
2. ‘Coming to the conclusion’	Once by a Wife	Not represented
3. ‘I quite accepted it’	Once by a Husband	Not represented
4. ‘It did nothing for me’	Once by a Wife	Not represented
5. ‘Coming here helped’	Not represented	Once by a Wife
Second higher order theme: Everything’s changed, we have to go from here		
6. ‘I would say I have changed’	Not represented	Not represented
7. ‘Taking over the reins’	Not represented	Once by a Wife
8. ‘Take it as it comes’	Once by a Wife	Not represented
9. ‘Coping very well’	Not represented	Once by a Wife
10. ‘I wouldn’t mind doing it all again’	Not represented	Once by a Wife

Appendix 3. Representation of Voice (Daniels et al., 2007)

Themes	PWD Voice (Jane)	Spouse voice (Tom)
Theme 1. Perspectives and preparation for Future Changes	Not represented	Represented twice
Theme 2 Family Influences and Social Support	Represented once	Not represented
Theme 3 Life Evaluation	Represented once	Not represented
Theme 4 Experiences with AD		
4.1 Role changes	Not represented	Represented once
4.2 Learning experiences	Not represented	Represented once
4.3 Daily experiences	Not represented	Represented once
4.4 Recognition experiences	Represented once	Not represented

Paper 2: Research Paper

**A systemic exploration of couplehood and continuity:
Negotiating the meaning and experience of dementia.**

Submitted

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Contents – Volume 1 (Research Component)

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Abstract

Using systemic ideas of circularity, reflexivity and narratives, this qualitative study explored couple's perception of continuity/discontinuity in their relationship and their response to those changes. It also explored the person with dementia's awareness of change in their partner. Three couples where the husbands were diagnosed with dementia and accessing services from an NHS community mental health team were recruited. Each partner was interviewed separately and the transcripts were analysed using Interpretative Phenomenological Analysis. Each couple has been presented as a case study highlighting the themes that emerged in each of their interviews. The findings are discussed within the context of the couple's perception of continuity/discontinuity and shared and divergent narratives. All the husbands and two wives felt their current relationships was similar to the pre-morbid relationship. One wife felt the current relationship felt radically different to the pre-morbid relationship. Clinical implications and directions for future research have been presented.

Keywords: *Dementia, Couplehood, Continuity, Systemic, Interpretative Phenomenological Analysis*

INTRODUCTION

It has frequently been suggested that the relationship between a person with dementia (PWD) and their spouse may moderate the impact of the dementia. Thus the overall rationale for this study is based on the suggestion in the literature that what happens in relationships is important to the emotional well-being and self-identity of both parties. A review by Cadell and Clare (2010) on the impact of dementia on self and identity suggests that dementia does impact the individual's identity. However from a systemic perspective the focus on the individual does not address how identity and meaning are shaped by relationships.

Hellstrom, Nolan and Lundh (2007) propose that Kitwood's (1997) idea of personhood, be extended to include the idea of *couplehood* where the identity of the carer and PWD are co-constructed within their relationship. O'Connor and colleagues (2007) argue for a better understanding of how the experience of dementia is socially constructed through beliefs and assumptions and how these affect the sense of personhood and the experience of dementia. Caron and Bowers (2003) highlighted the inter-relational processes involved in caregiving. A review by Walker and Luszcz (2009) on the dynamics of spousal relationships shows that supportive and close relationships may be a protective factor for the psychological well-being in older couples. Similar results from reviews were found by Ablitt, Jones and Muers (2009) and Quinn, Clare and Woods (2009) showing that the quality of the pre-morbid relationship impacts upon the experience of the relationship post-diagnosis.

Despite this, research into what happens to the spousal relationship is relatively limited and methodologically flawed. Traditionally research has taken a biomedical view of dementia characterised by phases and stages, disease progression and symptomatology. The literature is abundant with research on the physical and psychological demands of caring (Vitaliano, Zhang, & Scanlan, 2003). Some research such as that by Svanstrom and Dahlberg (2004) paints a view of relationships characterised by imbalance, futility, hopelessness and estrangement from the PWD. Traditionally the literature portrays a pessimistic picture dominated by stress- burden and deficit models, whereby dementia has been understood and researched in terms of separate caregiver/care recipient roles (McGovern 2011).

Changes in relationships in chronic illnesses are not always perceived negatively: For some spouses they are perceived as an extension of their spousal role (Badr, Acitelli & Carmack, 2007) and work by Heru, Ryan and Iqbal (2004) shows that some caregivers perceive more rewards from the relational changes than burdens. Work by Chelsa, Martinson and Muwaswes (1994) and Murray and Livingston (1998) also suggest that caring can be rewarding and meaningful. This suggests there is something about how couples perceive dementia that affects how they experience it.

One strand of this research relates to the idea of *continuity* in the relationship from the pre-morbid to the current relationship; and the moderating influence that this may have on the impact of dementia. The term continuity refers to how couples respond to the changes in their relationship; specifically to whether or not these changes have or have not led to a

climactic point where the spouse or relationship is perceived as being radically different to the pre-morbid relationship. A continuous relationship is one where there are changes, but these have not led to a radical re-appraisal of the relationship or a change in the bonds at the core of the relationship. A discontinuous relationship would be one where the changes have triggered very different feelings towards the spouse or the relationship. Wright (1993, 1998) proposes that continuity in affection provides a continued sense of meaning.

Continuity in relationships relates to better adjustment to the caregiving role, while discontinuity may be associated with a less constructive caring experience for both spouses (Walters, Oyebode & Riley, 2010). Continuity of relationships highlights the significance of the pre-morbid relationship and how this may moderate the current relationship.

Chesla et al. (1994) set out to explore the ways in which carers' interpreted their relationship with a family member with dementia. This research focused on the carers' interpretations of the PWD's ability to 'reciprocate' and 'relate' to a family member over time. Chelsa et al. (1994) identified three types of relationships characterised by differing degrees of continuity (Table 1). This research highlighted how mutuality in relationships and their interpretation may impact how relationships function over time. However the research did not focus on couple relationships.

Kaplan (2001) set out to determine the perception of couplehood identity with their institutionalised spouses. She proposed a typology that represented the degrees in perceptions of couplehood ranging from a strong sense of belonging to a strong sense of not

belonging (Table 1). This research highlighted how a carers' identity is partly determined in relation to their spouse. Although it is presented as a continuum the typology does not specifically measure change over time, it does however highlight the significance of the pre-morbid relationship and how the experience of caring and the meaning attributed to dementia is partly found within the couples' dynamics.

Hellstrom, Nolan and Lundh (2005, 2007) found that facing the dementia as a couple in the earlier stages may foster greater resilience and proposed that both partners actively 'work' at creating and maintaining a 'nurturative relational context'. They also suggest that couples construct their own meaning around the diagnosis and how their sense of couplehood may moderate the experience of dementia. Their research proposed a model based on three broad relationship phases (Table 1). As the notion of "couplehood" is central to this research, their model is presented below (Figure 1).

The findings presented by Hellstrom et al. (2007) seem consistent with work conducted by Keady (1999) and Keady and Nolan (2003) that highlights that couples "work" at reciprocity and identified four patterns of "working" (Table 1). These patterns highlight the active, joint and separate efforts that both the well spouse and the PWD engage in when faced with dementia.

Table 1 Summary of pertinent literature on couplehood

Author(s)	Approach	Who Interviewed?	Research design	Findings	Description
Chesla et al (2004)	Phenomenological	<ul style="list-style-type: none"> Spouses Family members 	<ul style="list-style-type: none"> Qualitative Longitudinal 	RELATIONSHIP TYPES	
				Relationship as continuous	<ul style="list-style-type: none"> Family members still define themselves in relation to their relationships and engage in rituals. Family members/spouses who interpret the PWD as still “present” and able to reciprocate.
				Relationship as continuous but transformed	<ul style="list-style-type: none"> Family members/spouses who are committed to the relationship and maintained contact with the PWD. Family members/spouses felt the PWD was changed and less able to reciprocate, but was still accessible at times.
				Relationship as radically discontinuous	<ul style="list-style-type: none"> Family members/spouses who felt the PWD and relationship had changed and was unrecognisable and experienced emotional distance from the PWD. Family members/spouses focus transitioned to providing good care.
Kaplan (2001)	TYPOLGY				
	Symbolic	Spouses	Qualitative	‘Til death us do	<ul style="list-style-type: none"> Spouses who have a strong sense of

Interactionism	part	couplehood and continue to feel part of the “we” in their relationship.		
	We-but	<ul style="list-style-type: none">• Spouses who still has a sense of “we”, but are starting to recognize the transition to decreased reciprocity from their spouse.		
	Husbandless wives / wifeless husbands	<ul style="list-style-type: none">• Spouses who still see themselves as married, but feel uncertain about the boundaries of their relationship.		
	Becoming and ‘I’	<ul style="list-style-type: none">• Spouses who now feel a stronger sense of “I” than “We”		
	Unmarried marrieds	<ul style="list-style-type: none">• Spouses who do not consider themselves to be part of the couple, while still remaining legally married.		
Keady (1999); Keady & Nolan (2003)				
RELATIONSHIP PATTERNS				
Grounded Theory	PWD & family carer (included some spouses)	Qualitative	Working together	<ul style="list-style-type: none">• Both partners recognize symptoms and share responsibility for seeking help.
			Working alone	<ul style="list-style-type: none">• PWD may have been hiding their difficulties/symptoms for some time. Both the PWD and carer may feel that they are working alone when seeking help.
			Working separately	<ul style="list-style-type: none">• Situation where the PWD is continuing to try to hide

				Working apart	<p>difficulties/symptoms, and the spouse is becoming 'vigilant' in trying to make sense of or respond to the circumstances.</p> <ul style="list-style-type: none"> Couples work apart due to difficult premorbid relationship or when their relationship becomes increasingly strained during the "working separately" stage
Hellstrom et al (2007)				RELATIONSHIP 'PHASES'	
Grounded Theory	<ul style="list-style-type: none"> PWD Spouse Majority Interviewed separately (some joint) 	<ul style="list-style-type: none"> Qualitative Longitudinal 		Sustaining Couplehood	<ul style="list-style-type: none"> Both spouses work at maintaining and enhancing their relationship through communication, being appreciative and affectionate, making the best of things and keeping the peace.
				Maintaining Involvement	<ul style="list-style-type: none"> The well spouse begins to encourage the PWD to be involved in activities, initially as a joint activity, and then through a gradual process of taking risks, the PWD either hands over or lets go, or the well spouse takes full initiative and takes over.
				Moving on	<ul style="list-style-type: none"> For some couples they may remain a "we" where the focus is on their relationship, but with the PWD

playing a less active role. Others couples move towards no longer defining themselves in terms of being in a relationship and move towards becoming an “I”. Once the person now defines themselves as an “I” they move on to new beginnings.

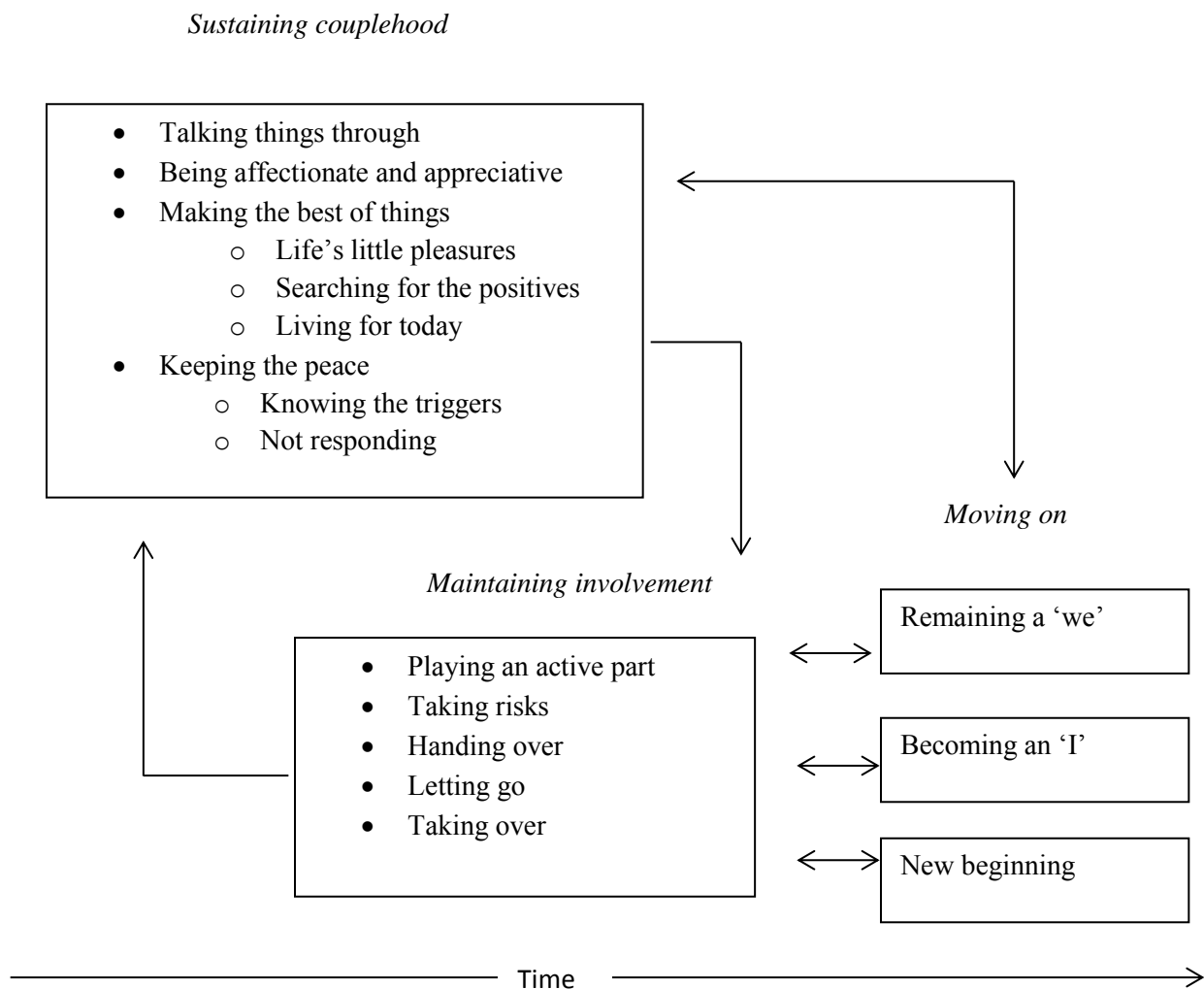


Figure 1. The dynamics of couplehood in dementia (Hellstrom et al., 2007).¹

¹ Permission was granted by Professor Lundh to reproduce the diagram.

A review by Walker and Luszcz (2009) shows that continuity positively impacts the well-being of both spouses. Work by Davies, Zeiss, Shea and Tinklenberg (1998) found that for some couples continuity in intimacy allows for couples to maintain their role identity. More work needs to be done to explore how a continued and shared sense of ‘couplehood’, or lack of the same, may mediate the experience of dementia.

In studies by Keady (1999); Keady & Nolan (2003); Svanstrom & Dahlberg (2004); and Hellstrom et al. (2005, 2007), the researchers interviewed both the family carer and the PWD and explored perceptions of this relationship and its possible effect on the experience of dementia. However the degree to which the voice of the PWD has been heard or accurately represented is limited in the research about relationship continuity. Some of the studies spoke only to the carer (e.g. Walters et al., 2010). Although Hellstrom et al. (2005, 2007), Bliesner & Shifflett (1990), Daniels et al. (2007) and Wright (1993, 1998) did interview the PWD, there are issues about how well their views are represented. This could have been for a number of factors such as couples being interviewed together, which may have given rise to the carer’s views being more dominant or difficulties related to cognitive functioning which may have made it problematic for the PWD to either adopt or articulate a position different from their spouse. Other factors may have included the increasing rate of

non-involvement in the research from the PWD in longitudinal studies such as that by Hellstrom et al. (2005; 2007).

Within Kitwood's framework (1997), interactions between the couple will be vital contributors to the PWD's sense of personhood. The impact of the sense of continuity/discontinuity on personhood is an issue that merits further investigation, but has so far not been explored.

Aims

I set out to interview both partners separately, with the rationale that this would allow the voice and story of the PWD to be more fully represented. The primary aim of the research was to explore couple's awareness of change in their relationship and their response to those changes. This included the perspective of the PWD which has not been looked at before. The secondary aim was to explore the PWD's reflexivity in the awareness of change in their spouse and if this was shared.

METHODOLOGY

Theoretical Foundations and approach

The research adopted a systemic rather than stress/burden approach to explore how couples make sense of their relationship in the presence of dementia. The systemic approach taken in this research is similar to Heidegger's view of the 'person-in-context' and the notion of the

inter-subjectivity which accounts for the ‘shared, overlapping and relational nature of our engagement in the world’ (Smith, Flowers & Larkin, 2009) that is typically espoused by phenomenological approaches. For the purposes of this paper some key systemic concepts will briefly introduced.

A fundamental principle of systemic approaches is the idea of *person-within-context* (Burnham, 1986). The experience of dementia can be understood within the context of the couple where each partner may have similar or different, yet equally valid views (Rivett & Street, 2009) of the impact on their relationship. The implication being multiple alternative truths (differences) and shared conventions of discourse (similarities) (McNamee & Gergen, 1992) around how couples view their relationship and dementia. As such, the use of narrative (Leiblich, Rivka & Tamar 1998) in creating meaning (intra- and interpersonally), lends itself well to the social constructionist nature of Interpretative Phenomenological Analysis (IPA).

Systemic ideas of reflexivity, circularity and feedback highlight that relationships are not static entities, but are systems that change and respond to feedback in a dynamic manner. Exploring reflexivity or the ability to take another person’s perspective is a key theoretical and practical technique for systemic researchers and clinicians, and highlights how meaning is made interpersonally and thus lends itself well to research with couples and continuity. That is, it’s through reflexive questioning and a partner’s ability to reflexively be aware of

their partner's experience of dementia, that we are able to explore whether the sense of continuity/discontinuity is shared.

Ethical issues

Ethical approval for the study was provided by an NHS research ethics committee (Appendix 1). As this research explored couple relationships there was a possibility that interviewees could have explored difficulties in their relationship. My experience in counselling and clinical psychology would have afforded the ability to manage minor distress and provide psychological support if needed. All participants were provided with the participant information sheet (PIS) outlining additional sources of support and the response protocol in the unlikely event that serious concerns arose.

There has been much discussion around involving people with dementia in research (Hellstrom, Nolan, Nordenfelt & Lundh, 2007) and numerous debates around the ethics of interviewing couples jointly or separately (e.g. Morris, 2001, Boman & Jevne, 2000; Forbat & Henderson, 2003). The weaker voice of the PWD in past research on relationship continuity could have been linked with joint interviews, as carers may have been more dominant or the cognitive difficulties of the PWD may have made it difficult for them to articulate their position. To counter these influences, couples were interviewed separately. It was also felt that interviewing the spouses separately would give them the opportunity to discuss their narratives in a way that they may otherwise not have felt able to do in front of their partner and might reveal any overlap of shared narratives through relational reflexivity

(Burnham, 2005) and circular questioning (Tomm, 1987), independently of the processes that may shape shared narratives if interviewed jointly.

All participants were aware that direct quotations would be utilised in publication and each was given the opportunity to identify parts of their interview that they would prefer not to be used. In the interest of anonymity participants were allocated pseudonyms.

Participants were identified by the local collaborator at the identified NHS CMHT who provided potential participants with the PIS. Participants were asked for consent to pass on their contact information to the researcher. Each couple met with the researcher for a joint information session, where the PIS and consent procedure were reviewed. Capacity to consent was informally assessed by the local collaborator and the researcher. The concept of process consent was also utilised (Usher & Arthur, 2003; Hellstrom, Nolan, Nordenfelt & Lundh, 2007), as such all participants were required to consent to being interviewed prior to the interview and at the interview. All participants were made aware of their right to withdraw at any time.

Participants

Recruitment was purposive. Three Couples were recruited from a CMHT in the West Midlands (See Appendix 2 for Recruitment Pack). All couples lived together in their family home. Basic demographic information, including the most recent Mini Mental Status Exam (MMSE) scores (Folstein, Folstein & McHugh, 1975), can be found in Table 2.

Table 2 Demographic data

Couple	PWD	Age (years)	Married (years)	Dementia Type	Time since diagnosis (months)	Most recent MMSE	Race	Interview Location
1.	Edgar Hazel	84 79	55	Vascular	2	26/30	White	Outpatient Hospital
2.	Callum Rose	76 64	40	Vascular	4	24/30	White	Home
3.	Albert Betty	85 81	62	Alzheimer's	4	27/30	White	Home

Inclusion and Exclusion criteria

Couples needed to be: Aged 50 yrs or more; in the relationship for a minimum of 10 years and living with each other prior to receiving a diagnosis of dementia. In addition they needed to be accessing services for dementia from the identified NHS CMHT and both partners needed to be aware of the diagnosis of dementia. Men with dementia were purposively chosen to further build upon our understanding of caring relationships.

Couples were excluded if: Either spouse was diagnosed with other severe mental health disorders, learning disabilities, or where either partner was institutionalised. This was an attempt to minimise potential confounding variables on the relationship and to ensure that all couples were able to reflect meaningfully upon their experience with dementia. Couples who did not speak English were excluded due to the complexities of carrying out qualitative work through interpreters. Also excluded were those who were unable to make satisfactory arrangements for the supervision of the PWD while the well spouse was being interviewed.

Procedure

Each couple met with the researcher for an information session, where the research procedure and aims were discussed. A copy of the recruitment pack can be found in Appendix 2.

Interviews

All interviews were recorded to allow for accurate transcription and for the researcher to focus on the participants rather than on documenting notes. All participants were given the option to identify parts of their interview they did not want to be used². Based on the concept of continuity/discontinuity, reflexivity and circularity, a semi-structured schedule (Appendix 3) was created and used to explore how each partner viewed their relationship.

Analysis and credibility

The transcripts were analysed using Interpretative Phenomenological Analysis (IPA) (Table 3). IPA is underpinned by three philosophical and theoretical foundations viz.

Phenomenology, Hermeneutics and Idiography. While IPA has clear theoretical foundations and a methodological approach (Brocki & Wearden, 2005, p. 87), it is also a flexible and adaptable approach (Eatough & Smith, 2006, p. 115, p. 120) to qualitative research. IPA is located within the social constructionism tradition which purports that people actively construct how they perceive their reality and experiences. IPA is thus interested in how people make sense of their personal and social experiences (Larkin & Thompson, 2011; Smith & Osborn, 2007, p. 53) and is helpful in eliciting individual stories through detailed interviews. As such IPA provides a way of exploring differences in how the PWD and

² Only one wife requested that some information not be used for the research, and the requested information was not transcribed.

couples perceive their relationship and is thus ideal for exploring how relationships are understood by the participant and the researcher (Smith, Flowers & Larkin, 2009).

Phenomenology stems from the collection of philosophical thought relating to how people experience a phenomenon, originating with ideas posited by Husserl and further developed by Heidegger, Merleau-Ponty and Sartre (Smith, Flowers & Larkin, 2009, pp. 12-21). In its original philosophical context, it involved a close introspection of the contents of one's conscious processes as a way of discovering the essence or meanings common to the thoughts of different minds. Its influence on IPA is evident in the notion that understanding can be gained from the study of the conscious experience of individuals (i.e. the way in which they experience the world); and that this understanding can encompass commonalities across several individuals.

IPA thus aims to make sense of how people make sense of their experiences, which also relates to its hermeneutic foundations. The German philosopher, Wilhelm Dilthey, applied the term 'hermeneutics' (borrowed from biblical studies) to his social philosophy which was concerned with the interpretation of human social behaviour (including what people say to each other) in the context of an assumption that such behaviour was an expression of the aims and intentions of those involved that were, in turn, developed from their attempts to make sense of their experience (Makkreel & Rodi, 1996). Hermeneutics is thus concerned with interpretation (Abulad, 2007, p. 11) and is represented by 'a range of different perspectives' (Smith, 2011, p. 58) represented by theorists such as Schleiermacher,

Heidegger and Gadamer (Smith, Flowers & Larkin, 2009, pp. 21-27). Its impact on IPA is apparent in the assumption that we can interpret what others say by reference to their attempts to make sense of their experience, and by reference to their conscious aims and intentions. A 'hermeneutic circle' (Smith, Flowers & Larkin, 2009, pp. 27-29) or 'double hermeneutics' (Smith, Flowers & Larkin, 2009, pp. 3, 35, 36, 80, 187) refers to the two stage process of interpretation, one where the participants are trying to make sense of their experience and another where the researcher actively tries to make sense of the participants making sense of their world (Smith & Osborn, 2007). This interpretative process refers to the process of understanding the 'dynamic relationship' between the part and its whole (Smith, 2007, p. 5). In couple research this may be how each spouse makes sense of their own experience on their own and reflexively in relation to their spouse. As this also includes the process by which the researcher interprets how the participants are making sense of their experience (Smith, 2007, p. 5), it is necessary for the researcher to reflect upon personal influences which may impact upon the interpretation process with the goal of being able to "bracket" off any preconceptions. This could be done by keeping a reflective journal after each interview, receiving ongoing supervision and providing a position statement as was done in this research.

In the context of disciplines such as anthropology and ethnography, 'ideography' originally referred to the intensive study of individual phenomena in their particular socio-historical context, with the intention of discovering broader principles that can be used to understand those phenomena in many different contexts. The influence on IPA is evident in its focus

on ‘individual’ and ‘personal’ experience (Smith, 2011, pp. 55-56), but with the assumption that this can tell us something more general about similar people. Thus the idiographic focus of IPA can effectively use and prefers a “small, purposively-selected and carefully situated sample” (ibid.). Smith, Flower and Larkin (2009, p. 51) suggest that a sample size of between 3 and 6 participants is acceptable for students and experienced researchers (ibid.). Smith, Flowers and Larkin (2009, pp. 52- 53) also advocate that “bolder” designs such as the one used in this research, using multiple perspectives (husbands and wives) and focusing on couple units may provide a “more detailed and multi-faceted account” and “generate rich and particular accounts” respectively; and that these may further acts as means of “triangulation”, thus overcoming some of the concerns with the idiographic focus and generalisation from small sample sizes that is critiqued by nomothetic designs.

Table 3. IPA Analysis Steps (Smith, Flowers & Larkin, 2009)

Steps	Description
1.	Reading and Re-reading of the transcripts.
2.	Initial Noting (Identifying descriptive, linguistic and conceptual comments).
3.	Develop emergent themes (identifying emergent themes through connections and patterns between initial notes).
4.	Searching for connections across emergent themes (looking for interrelationship between emergent themes).
5.	Moving to the next case.
6.	Looking for patterns across cases ³ .

All themes were discussed in supervision- only themes that met consensus were accepted as an attempt to minimise interpreter bias and to improve the plausibility and consistency of the interpretations.

³ step six included looking for patterns amongst partners in each couple dyad.

FINDINGS

Each couple is presented as a case study. I felt the nuances of reflexivity would be lost through the presentation of generic emergent themes across all couples. The emphasis of the findings is on whether the current relationship feels similar/different to the pre-morbid relationship, and if each partner in the couple is reflexively aware of and share their partner's experience/narratives of dementia. A list of all themes can be found in Table 4.

Table 4 Couple themes

Couple 1: Edgar & Hazel	Couple 2: Callum & Rose	Couple 3: Albert & Betty
Keeping up his activity levels	Complementarity	Separate but together
Trying to help his wife	Dependency	Intimacy
Dependency	Communication	Aging and Ability
Wanting to be with his wife	Intimacy	Caring and looking after
Communication	Caring and looking after	Effect on wife
Affection and Intimacy	Effects on wife	
Caring and looking after	Intentionality	
Effects on wife		

COUPLE 1: Edgar and Hazel

The general features of the relationship and my reflections on how the couple presented are illustrated in Box 1.

Box 1. General features and interview presentation: Edgar and Hazel

This couple has been married for nearly 55 years. Both Edgar and Hazel are from the North East of England and moved to the West Midlands in the mid 1960's. She worked as a Potter and now teaches yoga. Edgar was an engineer. Hazel insisted that she was interviewed first, and was pleased that while Edgar was being interviewed she would be able to have some time to herself to go shopping. They both arrived separately at the interviews. Edgar found the interview difficult and he was offered breaks; all of which he declined. His impairment seemed more extensive than originally assessed in the information session. During the interview Edgar's answers were comparatively short and less concrete than his wife's and at times seemed tangential to the questions. As such his voice is represented mostly through paraphrase than direct quotations. Where his intentions were clear, his voice has been represented by direct quotations. At the end of the interview he was concerned that he had not been much help and wanted to make sure that I knew it was not that he had not wanted to help, but that he felt he had not contributed enough. Hazel first noticed that '*something*

[was] not quite right' and persuaded Edgar to see the doctor. Edgar was diagnosed with vascular dementia five months prior to the interview but he describes experiencing memory difficulties for a couple of years. While their relationship is underscored by traditional roles, they had negotiated a life that was characterised by equality and shared and separate activities prior to the onset of dementia. They have always shared the household chores and routines, each doing their separate bits in the house. The role and importance of family seem to be central to their shared sense of identity and they both seem to have a sense of planning for the future and the role their family will play in assisting them.

A description of the themes relevant to this couple are presented below.

Keeping up his activity levels

The pre-morbid relationship could be characterised by an active lifestyle, with each partner engaging in joint and separate activities. They are both still members of the sports club, which they both feel is a central aspect of their life together. As both have always been active, the current reduced level of activity seems to be a source of frustration for Hazel:

...He just doesn't do anything anymore, he needs asking you know. And even when you ask, he forgets. It is frustrating. (Hazel)

Hazel feels she has to '*encourage*' Edgar to increase his activity levels. He has a shared sense that they are '*doing less*', and that she is '*probably doing more*'.

While Hazel makes '*excuses*' as to why she can't do something as a means to engage him in activity, Edgar says he tries to '*cover things up*' from her, although was unable to give examples. Both seem unaware that they are engaging in such behaviours. However he feels that Hazel must be aware of the changes in him as she is '*clever*'. Such behaviours suggest that both are actively working at sustaining each other's sense of their relationship; although he seems aware that his '*situation*' has changed the relationship somehow.

Trying to help his wife

There is a shared sense that he would like to do more as he does not want to leave '*problems*' for Hazel. She feels that Edgar is getting upset by his inability to do more recently. While he is aware of the impact of some of his behaviours, such as forgetting to mow the lawn, she perceives this to being similar to their pre-morbid relationship. He does not want to spend money as he feels Hazel may need it; she says he has always been careful with money.

Edgar now offers to help with ironing and cooking as he recognises that Hazel is tired. While he wants to help, he finds it difficult and needs more assistance.

Dependency

Hazel feels that he has become very dependent, which is epitomised by liking Edgar to a ‘puppy’, creating a sense of vulnerability and dependence:

He wants to come with me everywhere. So I ask why and he says “Well, I am not going to stay alone in this house”. He does not like being alone in the house anymore. And uhh, so that is like having a little dog on heel all the time sometimes. (Hazel)

The one thing that I have noticed, that when he has become very dependent on me, especially around finances, but in all areas really. (Hazel)

Yes, I mean he is umm, he will follow me around like a puppy. If I go into the kitchen to start the meal he’ll come and sit down in the kitchen which he never used to do. I hardly get any time to myself these days. (Hazel)

At times, Edgar does feel that he is more dependent on Hazel than before:

Bruce: *So are you saying that you are relying on your wife more?*

Edgar: *Probably yes. Yes.*

Bruce: *Are there other situations that you are relying on her more now than in the past?*

Edgar: *Yes, I think most things.*

Bruce: *Like what?*

Edgar: *Uhh like umm where are we going tomorrow? This is so and so. Why are we going there. She will say “I’ve told you.” You know, you know, I say “Can you tell me again?”*

It would appear that he is also aware that Hazel is doing more than he is:

Bruce: *What kind of things did you do in the past around the house that you are not doing now?*

Edgar: *Decorating. Anything. Uhh, I used to do alterations, within my capability I would be knocking a hole in the wall and putting a sliding door there, which I did. I could do all those things once upon a time but no way now.*

Bruce: *Is there anything that you are doing more of now that you never used to do?*

Edgar: *No, nothing I can think of.*

Bruce: *Would you both say that your relationship is equitable?*

Edgar: *Quite what?*

Bruce: *Equitable, that you are both contributing and doing things equally?*

Edgar: *I think so. She is probably doing more.*

Bruce: *Is that new or was that always the case?*

Edgar: *No, since the memory.*

Bruce: *How do you experience these changes?*

Edgar: *Experience them? Umm, I don't quite know.*

Bruce: *Is it difficult to kind of think about the things that are changing or letting go of things that you used to do in the past?*

Edgar: *I can't, I don't even think about it as I can't remember things I used to do in the past. That is it; the memory doesn't bring these things back.*

While Edgar is aware of changes to the level of dependence, he does not seem aware of the degree she is doing more or the intensity to which she feels he is more dependent:

Bruce: *Do you think your wife would say your relationship has changed?*

Edgar: *She might do. Dunno. She might do.*

Bruce: *How do you think she would think it has changed?*

Edgar: *Same reason, uhh, way that I do.*

Hazel attributes his increased dependence, and decreased activity, to him no longer being able to do so, rather than him choosing not to do so as he used to.

..it has changed in the sense that I am doing the things that he can't do anymore. Whereas before he chose not to do them. So there is a difference in that I think. (Hazel)

This transition in attributing the decrease in ability and increased dependence on her to ability rather than a purposive behaviour, seems to have allowed her to be more understanding:

He wants to come with me everywhere. So I ask why and he says "Well, I am not going to stay alone in this house". He does not like being alone in the house anymore. And uhh, so that is like having a little dog on heel all the time sometimes. He has to be near me all the time these days. I can understand it though, but I do need time to myself. That has just gone these days. (Hazel)

Wanting to be with his wife

While Edgar feels that '*being with his wife*' is more important now, she seems to be frustrated by not having any time to herself. This is a change to the pre-morbid relationship where both had separate interests and activities. However Edgar feels that it was '*doing things together*' that made their relationship '*excellent*'. While she shares this sentiment, she feels like she has no time to herself recently. Yoga has always been 'her' activity, but now she takes him along; partly as it increases his activity but also because he doesn't want to be home alone. Hazel feels this impacts the social aspect of yoga. This sense of always being underfoot is further felt on annual leave. While the couple still goes on holiday (as they have done for the past 42 years), and both still enjoy this, Hazel feels this is now feeling more '*claustrophobic*'.

...when you look back at other people who have split up, or perpetually bickering and all that, We love it when we just go in the caravan, but it is getting more claustrophobic now, because he is always wanting me around and its close quarters in there. (Hazel)

Communication

Communication is another area where change has occurred. In the past, Hazel feels that they communicated well, which has changed as she feels there is no more

conversation. Although she has always felt that Edgar should be able to ‘*read*’ her, she now feels that he ‘*doesn’t take in anything*’ and that he is ‘*not really there*’.

Edgar seems aware of the change and acknowledges he is not able to ‘*pick up on*’ Hazel’s comments and knows her comments ‘*don’t stick*’ anymore. Edgar feels that Hazel is only sharing ‘*25 percent*’ now; this could be his sense that she is not sharing the impact of the dementia with him, such as feeling more tired. She believes that she can not share and is careful not to pose the effect on her being related to him or the dementia. Hazel no longer shares as she feels it will alarm him or that it is futile as he changes the topic and feels like it is ‘*talking at him*’ now. Hazel misses the conversation and describes the lack of conversation to be ‘*quite lonely*’. Edgar is not aware of this and asserts that they ‘*talk about most things*’, although he doesn’t like talking about dementia:

We are both aware of it. So there is no point in talking about it. I don’t like talking about it to be quite honest, as I am annoyed at myself for becoming like this. (Edgar)

Affection and Intimacy

Both of them have a sense of continuity through rituals that they have always performed. While both acknowledge that they are no longer engaging in sex, they both still feel close which is demonstrated in them valuing what Hazel terms the ‘*sneaky cuddle*’, or Edgar’s account of making sure they have a ‘*hug and kiss every*

night and every morning'. Both of them have a shared narrative about sex having stopped due to reasons other than dementia.

We still have a sneaky cuddle, but we haven't had, umm you know, full sex, if you like. Umm, and so, I know that this might sound silly to you, but in the morning when we wake up, we always, always have a cuddle, and we never go to bed without a kiss goodnight, you know. (Hazel)

...we still, have a hug and kiss every night and every morning. (Edgar)

Both are still positive about their relationship and each other. Edgar feels they have a '*brilliant*' relationship in spite of the problems' and '*wouldn't have changed [his] wife for anything*'. Hazel still feels that they are '*everything to each other*', and that he is a '*very caring, very lovely man*'.

Both of them still have a shared sense of a strong foundation:

As far as I am concerned it is a superb relationship and that I would want it to continue and continue. I just hope we both go on happily for a long time. (Edgar)

And because we are very, very, well we've got, at the bottom of all this. We've got a superb stable relationship. You know, we have had, all the time, and it has got stronger with time over the years. You know, as you grow up together. (Hazel)

This shared idea of the pre-morbid foundation seems to mediate the experience of dementia on their current relationship. While dementia has created some changes, the couple are working at sustaining the areas that feel familiar.

Caring and looking after

Hazel feels that she is caring for him, but that the changes have been so gradual that she hasn't noticed. She feels that '*he is still [her] life*' and that while she has assumed caring responsibilities, that she has always done so, and feels that it is the duty of a wife, and is happy to do so.

Bruce: *So you have caring responsibilities now?*

Wife: *Yes, absolutely. He is like a little puppy that needs looking after. But I have always cared for him. It is what wives do. I don't resent it.*

This seems to highlight how couples negotiate the meaning of dementia, by experiences in their pre-morbid relationship. Caring seems to be a relational construct familiar to this couple, where he cared for her in the past, and she cares for him now. While Edgar is aware that he is more dependent, he does not share the idea that she is caring for him. This becomes evident below where he conceptualises his future relationship. While he acknowledges changes, he positions himself looking after Hazel by planning to not leave problems and attributing a future where he is no longer present due to aging and not dementia. One interpretation is that while he expects changes to occur (due to aging), that his construct of his future-self is based on his construct of his present-self, suggesting that he does not currently perceive himself as being cared for:

Bruce: *We have thought about your relationship ...what do you think it would be like in the future?*

Edgar: *I am hoping she can continue to tolerate my problem.*

Bruce: *What are your fears for the future?*

Edgar: *The things we all have for our age. I just don't want to leave my wife with a lot of problems. Umm, I do know we got a good family around us, and I know they would jump in and help.*

Bruce: *When you say you don't want to leave your wife with a lot of problems, what does that mean?*

Edgar: *Well, selling the house and all that sort of things.*

Bruce: *Does that mean when you are thinking about the future, that you think your wife will be left behind?*

Edgar: *Yes, I do think that as of course she is 5 years younger than me. It is only on that basis.*

Effects on wife

Pre-diagnosis Hazel was becoming increasingly irritated with him as she felt his behaviours were intentional. She suspected dementia as she was aware of the changes that had occurred in her brother's relationship. Through comparison she is making sense of the changes, prior to knowing the diagnosis, but also to how it has changed the way they are living.

Bruce: *So what has changed from how the relationship used to be like?*

Hazel: *I can't be me anymore. I can't be the same person. I know I have always been a fairly patient person. Then I went through this time of getting very irritated with him as I just felt that he was bored, wasn't listening and that's when I was getting very irritated with him. I realised it was more than just that, and also seeing my sister-in-law and brothers relationship change; I knew what the problem could've*

been. It has changed. It had to change. They both led independent lives and then after dementia they both got closer.

Bruce: *So where they got closer, would you say that is the same for your relationship?*

Hazel: *No, not closer. We have always been very close. Umm, it is a change of the way we are living, because there is one thing that he does, and I don't know sometimes if I should mention it or not. When we are in company, sometimes you would not even know there was anything wrong. I say to him, "Just stay, sit with a smile on your face, just look like that and make good, just be a good listener. People always like a good listener". But he fantasises, which he never used to do.*

Bruce: *Fantasises?*

Hazel: *He now imagines we have been to places, done things that we haven't. In Brighton where we stay, overlooking the beach. And we know this chap there and here, and he runs this lifeboat. [Edgar] will now say to people that we have been on the lifeboat. We had arranged to go, but [Edgar] got ill and we never did do it. But he is always telling people "Oh yes, we went on a lovely trip on the lifeboat."*

Bruce: *Is this something new?*

Hazel: *Yes. It's embarrassing sometimes. I find I have to tell him that we never did it, or that we have never been there.*

Bruce: *Do you talk to Edgar about some of these feelings?*

Hazel: *I don't know really. In company I try, but I'll say things such as "Oh we didn't actually make it, I was trying to arrange it but you were poorly". But then he still comes up with it in a different kind. I have to always set the record straight these days.*

One interpretation is that this has created a power difference from the equitable pre-morbid relationship where she feels that she is now responsible for most things.

Edgar is aware of some change and feels that Hazel is more irritable due to him:

Bruce: *Would you say your relationship has changed since how it used to be?*

Edgar: *Yes, only that my wife is a bit more irritable than she used to, uhh, because of me.*

Although he can acknowledge that Hazel is more irritated and that occasionally they get ‘*frustrated*’ with each other, he feels they are always ‘*agreeable*’, can’t remember specific examples of discord, and attributes their frustration to aging. Perhaps his interpretation of Hazel’s feeling that she is always having to set the record straight is that she is the one who is able to clarify things and provide ‘*answers*’.

Summary

A summary of the findings for this couple can be found in Box 2.

Box 2. Summary Edgar and Hazel

Perception of continuity

Despite changes to their relationship, the couple has a shared sense of continuity in their relationship. This is demonstrated by:

- Both are engaging in furtive behaviours to sustain each other’s sense of their relationship.
- Both share a sense of couplehood by engaging in rituals e.g. both engage and value being affectionate with each other.
- Both still trying to engage in previous lifestyle (e.g. sports club)

- Both are still very positive about each other.
- Both are positive about the strength and foundation of their marriage despite the effect of dementia.
- Hazel feels she has assumed caring responsibilities, but views this as being the duty of a wife, is happy to do so and feels she has always cared for him.

Shared narratives

Both Edgar and Hazel recognise changes in their relationship:

- Both recognise a decrease in activity levels.
- Both share the sense of Edgar becoming more dependent on Hazel.
- Both feel that the content and dynamics of communication between them has changed.
- Both are very positive about one another.

Divergent narratives

- Edgar attributes changes in the relationship to aging and not dementia.
- Edgar does not share his wife's view that she is caring for him.
- Hazel feels she is always around, while Edgar wants to spend time with Hazel and feels this has always been the case.

COUPLE 2: Callum and Rose

The general features of the couple's relationship and my reflections on how the couple presented are illustrated in the Box 3.

Box 3. General features and interview presentation: Callum and Rose

This couple has been married for forty years. Rose is 12 years younger than Callum. Their marriage is characterised by traditional roles, both which feel they were expected and were happy to fulfil. While Rose views herself as a practical person, she has always viewed Callum as being particularly clumsy. Rose uses a metaphor of 'two sides of a coin' to show how different, yet complementary both of them have been in the past. While both of them share the same narrative that neither are romantic, they have always done things together. Callum was diagnosed after Rose insisted that he see the doctor. Rose liaises with the medical professionals around Callum's dementia. The pre-morbid relationship was defined by a work identity where they both shared common friends who were also clients at Callum's self-owned company. Work provided this couple with the financial means to engage in a very active social life; which has since diminished after retirement and getting older. Callum's work gave the couple an identity and gave him a sense of purpose and a role. Rose worked in marketing as the children were growing up. Callum was not happy about Rose working and felt that there was no need for her

to work, and that it was her choice and not necessary. This was a source of acrimony in their pre-morbid relationship. At the time of interviewing, Callum was still doing some consultancy work and Rose was still working. Rose felt this change in roles, with her being the breadwinner had impacted their relationship as she felt she was juggling the responsibilities of being a wife and working; while he was not content about her working and would thus not help her. Callum's current consultancy work provided a sense of role and purpose for him, and both enjoyed the fact that he could still contribute to the household finances. Both Callum and Rose engaged with the interviewer in asking questions; seemingly as a means to check that each of them were right. Rose spoke about her relationship in a matter of fact manner; there were times that she was visibly upset by talking about the changes to her relationship. Callum seemed to think about Rose a lot during the interview, and gave a general sense that he was questioning whether she felt the same.

A description of the themes relevant to Callum and Rose is presented below.

Complementarity

It is clear that in the pre-morbid relationship that Rose did everything around the house. However this was expected and perceived by both as being ideal. There is a sense of complementarity and team work.

...we have always been two sides of a coin. When he was working, it was always he was finance and I was the labour. He worked and I stayed at home. Which was the standard model in the sixties; it was what I expected to do and it was what he expected his wife to do. Umm, it was like that and I've always been the one that has done everything except work. Umm, decorating, plumbing, gardening, mending, fixing, sorting, all of it really. He just walked away with his clean shirt on and came home at night for his dinner. But that suited us both, it was perfect. (Rose)

However for Rose the relationship now feels different as they are no longer complementary.

Rose: *...we have always been a good team, I think.*

Bruce: *A team? Is there teamwork now?*

Rose: *Yeah there is to an extent, but it's not. Umm, oh no, let's be honest here Bruce, it's not a team.*

Bruce: *What is it?*

Rose: *It is me dragging him along behind.*

Bruce: *What do you think he would say?*

Rose: *Probably the same thing. And I say that advisedly, as I try to empower him. I try hard not to deskill him. But parallel to the dementia, is the man that he is, the man who is really clumsy, the one who can't put a nail in the piece of wood, who doesn't see anything and who never has.*

Callum does not have a sense that Rose feels they are no longer complementary.

While he is able to recognise a change from the pre-morbid relationship, he feels that they both get on with things and that he does help Rose. Although he gives the impression of teamwork, he does recognise that Rose has to ask for help, suggesting that maybe he is not recognising the need to help.

Callum: *Oh she does all the cooking. She has always done the cooking, but I might help her every now and then, and I do the washing up and tidying up and that sort of thing. I don't help much with the cooking as I am not really much into cooking.*

Bruce: *What about helping with cooking prep like peeling the potatoes or veggies?*

Callum: *Oh yeah, yes yes I do that.*

Bruce: *Is that something that you have always done?*

Callum: *No as I was working and she wasn't. I didn't do much then to be honest with you.*

Bruce: *When did that change?*

Callum: *After retirement*

Bruce: *After you retired what was it like both being at home?*

Callum: *Well we just got on with it. Now I just get on with it, it depends really, if we have people coming really. We entertain quite a bit, so I'll do maybe the potatoes, or prepare stuff that I could prepare.*

Bruce: *Do you do that by yourself or does your wife have to ask?*

Callum: *She probably has to ask me to do it to be fair. If she has plenty of time she wouldn't ask me to do these things. It's only when she is rushed for time.*

Bruce: *When she asks do you just get on with it, or need some help?*

Callum: *Yes I just get on with it and go ahead and do what I've been asked to do. If I needed help I don't mind asking her for it. We get on well like that; I hope she is saying that as well (laughs).*

Bruce: *What do you think she would say about what we just talked about cooking and preparation?*

Callum: *She would say she does the cooking but occasionally that I would help her. She would probably say I always help if she wanted or asked for it.*

Dependency

Rose now feels that Callum is more reliant on her and that she needs to prompt him and is annoyed at his inability to follow prompts.

I have to prompt a lot more on everything really. Umm, "Please don't cut the vegetables up, just peel and leave them in the water", I'll come back and he's cutting them. "I told you not to cut them up, please, please don't cut them up!", "Oh yeah, sorry, forgot". Because that sounds very petty doesn't it? But I don't want them cut up; I just want the darn things peeled thank you very much. He is great at peeling and coring apples. He does a good job in the prep. He doesn't cook, he has never cooked. (Rose)

For Rose, the increased dependency has created a power imbalance. Although she feels that dementia has impacted Callum's ability, she is reflective about her

reactions towards him – suggesting that there are still areas that she feels that he is not so dependent.

Umm, it is now very very top heavy. With me on top, sorting everything, doing everything, thinking for the both of us, sourcing everything. I mean he can function, but it's a very limited level these days. I do try awfully hard to not go where I am not needed, but it's hard to know exactly where he is at or what he needs help with. I would wait and see. (Rose)

Assuming a training role feels very different from the complementary roles in the pre-morbid relationship and further demonstrates a sense of imbalance for Rose, where they both had distinct roles and functions; and where Callum was responsible and capable.

So I am training him how to do even the simplest of things these days. I've left him notes, little instructions, so I put it all out for him, and I leave the instruction. Say I'm going out to work, I lay it all out, I'll put the bowl out, the porridge with instructions on top. Then I'll label the soup for lunch, leave the bowl and instructions. Because it has to be torn and microwaved and all the rest of it. (Rose)

Callum is aware that he is more reliant and needs more instructions and strategies. However he feels he has never been good at some tasks, rather than it being the dementia.

Bruce: *I noticed as you are talking there that you have instructions there. What are they for?*

Callum: *Umm, what these? Umm those are just to help me get the TV stations. I am no bloody good at it; in fact I am bloody hopeless at it. So it guides me to find whatever it is that I need so I can watch what I want.*

Bruce: *Are those kind of strategies to help you remember?*

Callum: *Yes*

Bruce: *Was that something that you asked your wife to make for you?*

Callum: *No, she felt that she had to do it because I'm no bloody good at that sort of thing.*

Bruce: *Have you needed more strategies as your memory has gotten worse?*

Callum: *Probably has, yes.*

Callum is unaware of the impact of his increased dependence on Rose, although he has a vague sense that this may be impacting her negatively, but believes that his love for her somehow moderates the impact of being more dependent.

Bruce: *Do you feel that your relationship has changed in that she is doing more things for you?*

Callum: *Well it is noticeable that she doing more for me. And Uhh, it's noticeable that, but I don't know, I don't know whether she finds it harsh or anything like that, I don't think so. I could be wrong. I would like to think that I love her as much as I always did and would hope that she does the same.*

The relationship feels different to Rose as she feels that she no longer has alone time:

I still want my hobbies, Nothing, nothing stops me from painting. See, it is the fact that we are together all the time, and we have never done that before. I am never away from him Bruce, and I hate it. He always used to pop out, and I would get that golden hour to myself. I would have that hour or so on my own, and I don't get that anymore, and I really miss that now. (Rose)

Communication

Rose feels the relationship has changed as there is no conversation and she needs to initiate conversation which is different. For Rose this feels like they are motionless and not moving forward.

Bruce: *You mentioned earlier being no movement forward.*

Rose: *There isn't. Something has just stopped. He has no conversation any longer, He no longer raises any issues or a subject, I always have to lead the conversation. We have always been able to sit all night and talk. So I find myself always having to initiate the conversation now.*

She feels that initiating conversation is tiresome and futile and that the lack of conversation feels lonely. She accepts some responsibility for the decrease in conversation.

It's just too much work, there's really no point now in initiating those kind of every day conversations anymore. I just think, oh wow, I can't

be bothered. Bruce, I'm not sure you could understand but that is a very lonely place to be you know. (Rose)

This feels different to when Callum always wanted the conversation to continue. She is feeling frustrated that conversation is now repetitive; and feels this is not only in their relationship, but in others too.

Rose: *...Bruce, so don't ever forget this, first of all he is Irish; generally Irish people are happy people and they never want the conversation to stop. So they will always try to dredge up a subject to keep it flowing; which goes against what I was saying to you before, about us never being able to have a conversation together anymore. If there were three people in the room, that conversation would never stop, but he might very well say to you "Are you married Bruce?", and then ten minutes later ask you the same thing. And he will do this, and our friends are great they will just answer his questions. So there is that.*

Bruce: *Do you just re-answer him?*

Rose: *Yes, I do but my little 3 year old grandson got very cross with him in Belgium: "Grandpa, I told you that already!" Then he would reply "Oh right you have my son." Then he would say "I'm not you son!" "Yes I know but it's a nice name", "Yes, alright then grandpa".*

Bruce: *Do you think that was him acknowledging what had been said or that he recognised he had already asked the same thing before?*

Rose: *Acknowledgement really, I don't think he is aware he asks people things over and over.*

Bruce: *Do you think he does the same thing with you when having a conversation?*

Rose: *Yes, it's always the same conversation Bruce, there is nothing new that we discuss.*

There are moments where she feels that they are still able to bond and convey a feeling of shared connection. Such moments are felt positively and similar to the pre-morbid relationship.

Bruce: *How much do you think he is participating or engaging in conversation?*

Rose: *Quite well if it is a subject that he likes and we both are interested in. A classic example, I was tidying up the porch at the weekend, and I lifted up a plastic bag that had been shoved in the corner, and there was a toad underneath it. A beautiful tiny little toad, how the heck it got in there, we haven't still worked it out. But I called him and said "Look at this" and we were both absolutely enchanted and we discussed it, I picked it up, we took it down the garden, we found a place for it, and we were thrilled about that. I loved it! He loved it. I miss moments like these nowadays.*

Bruce: *So for a moment*

Rose: *(Interrupts). Yes it was like dementia wasn't there, you see, we were in the moment and I saw my husband again, how he used to be, passionate about something. He was delighted and I was delighted to see him like that. I mean also he filled up the bird feeder the other day and both of us are really chuffed because the gold finches are now back. So in the moment and immediate stuff we connect and we can talk about.*

Callum feels they still talk about everything, although less so about intimacy.

Callum feels that Rose is withholding things to protect him. Callum has attempted to talk with Rose about this, but feels she ignores him. He could be picking up on her sense of futility in conversation. While he thinks she is withholding, he seems to dismiss this as a consequence of a long marriage – suggesting an expected decrease in conversation amongst spouses over time:

Callum: *We talk to each other, we talk about everything from family, about how I am, how she is. We don't talk that much about sex I don't think. We used to though. Umm, we uhh.*

Bruce: *Sounds like you still talk about a lot of things. What things aren't you talking about anymore?*

Callum: *Well sex. I think we talk about anything else really.*

Bruce: *When you are talking, are you talking about feelings and thoughts?*

Callum: *I suppose, don't know really*

Bruce: *Do you think your wife talks to you about her thoughts and feelings?*

Callum: *I think she talks to me about some of her feelings, let's put it like that.*

Bruce: *Mmm, some?*

Callum: *I think she probably holds back on some things.*

Bruce: *What do you think she is holding back on?*

Callum: *On how maybe she may know more about how I am, umm, I know if the doctor or if the surgeon or whoever it was at the hospital or maybe the doctor tells her things, she may not tell me about them.*

Bruce: *Why do you think that would be?*

Callum: *I think she would not want to worry me and knowing or think that I would be worried about what they had found. Umm, but, uhh, I think she was the one; yeah that is what it would be.*

Bruce: *So you think that is the case?*

Callum: *I think she knows more than she has told me.*

Bruce: *What is that like for you?*

Callum: *I just accept it.*

Bruce: *You just accept? Do you talk to your wife about the feeling that something is not being discussed?*

Callum: *Umm, I may have mentioned it once or twice, but not as a daily thing or uhh, I think I may have said: "I think you might know more about me than you are talking about", but I think she then either ignores that questions because don't forget we have been, we were, umm, married all those years and we were umm, together, what for a uhh, a year or so before that. That's a long time.*

Callum feels they are talking less about sex and attributes this to the natural progression of couples to talk about sex less often, rather than to dementia. Callum feels that they converse and thus does not share Rose's feelings.

Bruce: *What do you think your wife would say about the things we just talked about, like umm, the type of things you talk about?*

Callum: *I think she would probably say that we do talk. Umm we talk about so many things really. We don't talk about, uhh, not now. We used to talk about sex a lot, uhh, not now. We used to talk about sex a lot, but I think that was probably about forty or so years ago now when we were first married and it was all about sex, you know.*

Intimacy

Although Rose feels that she has a marital duty, the relationship feels so different since the dementia that intimacy is now distasteful. Although she asserts that this is something that they both have to accept, she is able to think reflexively on the impact that this may have on him. She feels that she could continue on as it is now unless she was unable to manage some behaviour.

...But as far as being with him, I don't mind. That's marriage; it's just the deal Bruce. Although Bruce to be honest it's not a spousal thing any longer you know. To put it bluntly, we have no sex life left. I am sure you would have liked to have asked that question, but I can tell you that's a fact. For various reasons I simply couldn't anymore, umm, because it would almost be like having sex with a child. I would find that quite distasteful and I wouldn't wish to do that, and I think he has accepted that I'm afraid. And anyway, he is not able, so that is the end of that side, and Bruce, that really hurts him. But I think we have both had to just accept that is never going to happen anymore. I'm still his wife, but it's not anything that I don't want to do anymore. Well that's gone. Apart from that, until he became violent or roaming around, that's where I wouldn't be able to manage anymore. Then I would consider having to put him into care. As if I can't sleep, or he is getting up and roaming. (Rose)

Callum is aware of changes in intimacy and asserts that he still cares for Rose and that sex has been replaced with an emotional intimacy. He attributes this to growing older and sex not being as important and not dementia. He is not aware of Rose's view on intimacy and still feels that there is warmth between them. Callum hints at the possibility that Rose may not share his view.

Bruce: *So there's something about intimacy and changes to that over time?*

Callum: *It probably has, but still there.*

Bruce: *What's still there?*

Callum: *Well, my caring for her is still there.*

Bruce: *Is caring an emotional intimacy rather than a physical intimacy?*

Callum: *Yes, yes it is. I care for my wife intimately; there is emotional closeness and intimacy there still.*

Bruce: *Has that changed in any way?*

Callum: *Umm, I don't think it has. We discuss what we do and where we go and who said what and all that, that sort of thing still. No I don't think it has changed; well I would like to think that it hasn't changed; whether she is saying the same thing or not I wouldn't know; but I think it is from my point of view.*

Bruce: *So what about the physical intimacy then?*

Callum: *Probably where the most change has happened really. We used to talk about sex a lot. Less talk now.*

Bruce: *Why do you think there is less talk about this now?*

Callum: *I think you are growing older to be honest with you, and it's not as important. When I say important, umm is it important? Is that the word? I don't think it is really. Relationships develop over time to a different kind of relationship. Umm, before, let's be fair about this, when you first meet your wife or the first couple of years, or however many years, you totally walk around naked, with no clothes on and all that sort of thing. But I noticed that doesn't happen so often now.*

Bruce: *Mmm, why do you think that is?*

Callum: *I don't know why really, I think they just got used to you.*

Bruce: *So thinking about the impact of dementia on your relationship. When you or your wife first noticed the difficulties, do you think that impacted intimacy?*

Callum: *It possibly has, It possibly has, but I don't know. It is not deliberate or anything I don't think. It may well have happened like that.*

Bruce: *What kind of impact do you think it would have had?*

Callum: *Ahh, it would have meant that was no sort of end product so to speak. There is no end product, we don't talk about as much about sex as we used to. We now talk about everyday things. It's not that we no longer hit it off; I just don't think we don't talk about sex as much now. So there is still very much warmth there, well at least from my point of view at least.*

Callum feels that there is a possibility that they could still be intimate, and thus does not share Rose's view:

I don't know how she would feel about it, I mean I don't think like I used to think, like I'll go home tonight and jump into bed. I don't think like that anymore. I am not saying that it would never happen, but it hasn't happened recently (laughs). (Callum).

Caring and looking after

Rose feels that she is caring for Callum, and uses the simile of being 'like a mummy'. While the image of mother may conjure ideas of nurturing and untiring sacrifice, her use of 'mummy' would suggest more negative connotations, such as signifying an imbalance which she finds dreadful.

Bruce: *Would you say that you are both still very complementary?*

Rose: *Umm, no. I'm the mummy now.*

Bruce: *So it sounds like there has been quite a change in position or role?*

Rose: *Yes, it has been absolutely awful. The upheaval has been absolutely dreadful.*

Caring seems to be veiled in traditional roles and power imbalance. Caring is a familiar relational construct, where she feels that Callum looked after her and that has now switched.

Bruce: *So quite traditional roles prior to memory difficulties and quite a change since then. What's that like?*

Rose: *Well early in our relationship he was looking after me, now I am looking after him. I'm the mummy now. Well I am now the main, umm, I am the breadwinner. So I am now the household reference person. I am now the head of the household.*

Callum feels that there has not been a major change to his relationship, but can recognise a change in Rose's attitude towards him, but does not perceive this as being cared for.

Bruce: *How do you feel your relationship changed or stayed the same since having memory difficulties?*

Callum: *That's a difficult one to answer. There have been some changes, but we still sleep in the same bed, and we still have the same meals at the same time sort of thing. So from that point of view, we are the same. We still do the same things, I take my dogs out. I think I'm okay really. I don't think there has been that major a change really to be honest with you.*

Bruce: *So most of it has stayed the same; what parts have changed?*

Callum: *Probably her attitude towards me in a way that changed.*

Bruce: *Meaning?*

Callum: *Before I did my own things without reference, now she wants to know how I am, what I'm doing, where I'm going because she seems to be more inclined now to be more careful if I go out with the dogs. If I go out with the dogs and I'm late or that sort of things, she is probably wondering where I am now, sort of thing.*

Bruce: *Maybe more concerned or worried lately?*

Callum: *Umm, not worried, she trusts me completely. Probably more concerned, but umm, concerned that I'm not getting into any scrapes.*

Effects on wife

Rose feels that doing everything now feels different to the complementarity of the pre-morbid relationship. Rose is distressed by the thought of things getting worse and not being able to manage in the future. She feels that caring has been forced upon her. There is a sense of duty in caring, and that this is difficult as she still views herself as his wife.

Rose: *I think I'm on a tableau, umm, a plateau, I think this is it now. I think this is it; I don't think it will get any worse. I think this is my life in the future right now. And I'm tired. If he gets worse, as I said already; if he got to the point where I couldn't cope with it then I would have to take a hard decision, but if he keeps going like this, then we'll keep going like this. This will just be the way that it is.*

Bruce: *Take a hard decision?*

Rose: *I would have to have him put into care (tearful), I'm not, I'm afraid I don't think I'm one of these people who could completely immerse myself twenty-four-seven caring for somebody that couldn't care for themselves. I don't want to stop work until I'm forced to because I can't do my job any longer. Umm, because that is my sanity Bruce.*

Bruce: *Caring? Sounds like there is a degree that you feel you are caring for your husband. Do you consider yourself a carer?*

Rose: *Umm, I'm the mummy and mummies care for their children. So yes, I consider myself to be caring for him right now.*

Bruce: *It also sounds that there is so much more to your relationship than just caring, is that correct?*

Rose: *There are still parts of the relationship that is important to us both. Oh yes, the caring side of it has been forced upon me if you like because of his needs. But he hates it; he hates the fact that I have to do*

anything for him or having to say anything. He really hates me having to do it.

Bruce: *What about you?*

Rose: *Oh Bruce, it's the deal isn't it? You get married, for best for worse it's just the deal really. I mean I'm his wife, it's the deal. It's what you buy into when you get married.*

Bruce: *What's that emotion there?*

Rose: *Oh it's not emotion; it's just me being pragmatic I guess. It's just the deal. We signed up for this and this is how it's gone.*

Bruce: *What's the feeling? Is it a burden or an extension of being a wife?*

Rose: *Oh that last one is it. On occasions it's not caring for him Bruce; it's having to do everything...*

Although both feel they can continue he seems unaware of the impact of dementia on Rose. Although he knows his behaviour were worse due to the dementia, he feels he is now getting better. He is not aware that Rose is thinking about a difficult future and the possibility of residential care.

Bruce: *Thinking about the future, what are your dreams, goals, hopes, expectations?*

Callum: *Well before this happened, my expectations that I continue, my hopes are that I continue as I am at the moment, because I think I am better than I was than before I went away when I wasn't that well. I gradually notice myself getting better and being in good form, and all the usual. And I have continued with that to be honest with you. And I feel that is how I want it to continue.*

Rose highlights the impact of dementia on her daughters. She asserts that she feels similar and feels that he is no longer the person she once knew.

Rose: *Umm, I'm weary Bruce; I'm just weary of it, of him, because there is no forward movement in him any longer, he just seems stuck now where he is.*

Bruce: *From dementia?*

Rose: *Well my daughters, one lives in Belgium, the other one local, but they both would tell you that they have lost their father, tells you that he's gone now. And I feel the same. It's no longer him.*

Rose likens Callum to a lodger with special needs and a stranger, giving the sense that at times he feels so unfamiliar to her and extremely dependent.

It is like having a lodger with special needs. Bruce, that is what my life is like now. I have this lodger, this stranger in my house. (Rose)

Rose is struggling to make sense of some of her experiences, and is trying to negotiate a meaning of his aggressive outbursts in a way that she is able to assimilate it into her view of her husband. Callum's violence has initiated her thinking about the future.

Rose: *He is still my best friend; I wouldn't umm abandon him, unless I really couldn't manage it. I mean this episode on holiday where he was violent, he didn't actually, well he did thump me, but well, it was my leg he thumped so not really me. What I mean is, he sat down, umm, we were on the boat in a force eleven gale, you couldn't keep your feet and at one point he sat down on my replacement knee. And I yelled and he*

thumped and punched my leg. It wasn't me, he didn't know it was me. He was also barking mad at the time. I don't know where he was, but he did threaten me. He said "I'll put your fucking teeth down your throat woman, you telling me what to do", because I had to keep him in the cabin. It was awful, so if stuff like that, that I just couldn't manage, I would have to leave.

Bruce: *Is that about crossing boundaries? Sounds like some change you are willing to deal with, but not others, the one that cross those boundaries?*

Rose: *Well I couldn't never; I could certainly never function if I couldn't sleep. I have been awake since three o'clock.*

Bruce: *So that incident on the boat, that was quite disturbing.*

Rose: *(interrupts) yes it was horrendous.*

Bruce: *But it sounds like you are hesitant to attribute that totally to dementia?*

Rose: *No, except that this is now the third time that this has happened, so starting to think more and more its dementia related. This was by far and away the worst episode yet. I mean they did keep him in hospital for three days. And he was not really compus mentis on the way from Bilbao to my daughters place. After about four hours he started to tire and talk back as if he was in the 1950's, he said "Now when did Roisin leave Cork?" and Cork being a town in Ireland, she of course never lived there. So he was obviously thinking of somebody else, and I said umm, actually I can manage him quite fine when he is talking like that as if he is in the past, but I couldn't cope with the sleeplessness and I couldn't cope with the implied, umm, he is the gentlest man, I mean he has never even used to smack our children. I was a great one for disciplining the children, but he could never do it. And he has never raised a finger to me.*

Bruce: *So with all the other changes, the violence is a change that you would find difficult?*

Rose: *It is not a question of finding or it being difficult, if he turned violent then that would be that, I would not be able to keep going.*

Rose poignantly describes dementia as a fate worse than death, epitomising the impact upon her.

I had not expected this Bruce. I had expected to be married to an older man; I knew that would catch us up one of the days. But I never thought of him losing his mind. It never crossed my mind. He lied to me; told me he wouldn't make sixty five. All the men in his family died of heart trouble. So what do I do, I get his bloody heart bypass and save him from that fate worse than death, bloody dementia! (Rose)

Rose still thinks Callum is a lovely man but she feels changed in how she needs time away to be free of the role of wife and carer. Her use of 'baggage' suggests that her relationship feels very different to the 'perfect' pre-morbid relationship.

Rose: *You know Bruce, being in this situation with him, is nothing that I ever thought would happen to us. Its shit! It really is shit. It's so nice just to be able to talk to you today, because I miss the conversation. It's really just shit. It's heart-breaking because I don't have much fun anymore Bruce (tearful). I'm going to cry now, which is daft because we are at the end, but yeah, I don't have fun anymore. I get in the car you know, and I drive away, just going away, beautiful drive and my spirits lift as I drive away. What's that about? That's awful. That's just awful.*

Bruce: *Sounds like guilt?*

Rose: *It's guilt about leaving this, leaving my home and that lovely man out there, I just get out for four or five hours where I haven't got to think about it.*

Bruce: *Do you talk to him about this?*

Rose: *Oh no, god no. I don't want to hurt him. How would that be: "Love, it is great when I drive away"? No, no, but it is hard and that is why I have that holiday booked in March and boy am I looking forward to it.*

Bruce: *Are you surprised about your feelings and that you need time away by yourself?*

Rose: *No. Oh yes, when I drive away and feel that way, I don't like that. That's new for me. I don't like that. I've always gone on holiday on my own, because my interests are different to his, so like I went up to the peat district as I wanted to look at the caves and he didn't. So I did that by myself. I haven't done it in a very long time, but I thought I needed to get away earlier this year and so I went by myself to get away, on a cruise of the Mediterranean, and it was lovely. Umm and it was great because I didn't have to talk to anybody. What a relief! I could be nobody particular. I was just alone Bruce. Nobody particular. Nobody's wife, nobody's carer. I could just be me and no one else. I didn't have to explain myself. I didn't have to talk to anyone. No one knew me. I had no baggage. I was just me at a dining room table. It was anonymity in a crowd. It was lovely. And now I am pushing having three weeks away somewhere in March.*

Callum seems unaware that Rose thinks the relationship feels different and believes they are getting on fine – although he reflexively considers if she thinks the same. He is aware that Rose enjoys time where he is away, but does not attribute this to the impact of dementia.

Callum: *...I think she umm, I think we get on fine. I don't know if she thinks that or not. She has never said that she can't stand me being here all the time. She would never say that, but she has never said it to me.*

Bruce: *So you think she would never say it to you, do you think she feels that way?*

Callum: *I think she is always glad if I was out of the house for a period every day. I would umm, I know she likes being umm, well she doesn't necessarily like being alone, but she doesn't like being crowded in. Although I would never interfere with her work or anything like that.*

Bruce: *Is that something that you think has changed over time?*

Callum: *I can't recall it ever being a problem before.*

Bruce: *Is it a problem now?*

Callum: *No there is no problem, well, not that I know of.*

Bruce: *So it's just a general sense that maybe she would*

Husband: *(interrupts) that she would rather me not be here. But I don't try to interfere in anything that she does, or with her painting, and that keeps her very active. She loves painting and so on and so forth. And uhh, she just, I thought she was generally quite happy, but I don't know. She has never said to me that she hates herself, or hates us directly in that way, that she doesn't like us.*

Intentionality

Rose feels that Callum's behaviours are purposive and attributes intentionality to him not cleaning his hearing aid, walking mud through the house, not cleaning the toilet, not wearing appropriate clothes, drinking excessively or being 'more combative'. A feeling of intolerance is created through attributing intentionality.

Well it is like pulling teeth, isn't it? Umm he, but again you see, most of the problem is, is that he doesn't do anything. And he doesn't do anything because he doesn't want to do anything anymore as he no longer sees the point to doing anything. (Rose)

Callum is aware that there has been a change in the way that Rose is relating to him. His impression of the change seems to reflect how she is now attributing his

behaviours to being intentional; which in turns makes him irritated. There is a sense of stalemate between the couple in the circularity of forgetting and intentionality.

Bruce: *When you do argue, what kinds of things is it about?*

Callum: *Umm I don't know really. It's not usually what we are arguing about, but it's about attitude more.*

Bruce: *Attitude?*

Callum: *See if she thinks that I should know about it, and I don't that would make me a bit irritated. Because I'd say "I wouldn't ask you if I didn't know", "If I knew about it, I wouldn't ask you, and if you've told me, I've obviously forgotten about it!"*

Summary

A summary of the findings for Callum and Rose can be found in Box 4.

Box 4. Summary Callum and Rose

Perception of continuity/discontinuity

For Rose the Relationship appears to feel radically different from the pre-morbid relationship:

- Rose feels the relationship has changed as it is no longer complementary.
- Rose feels the increased dependency has created a power imbalance and no longer has any time to herself.
- There are moments such as the incident in the garden where Rose feels that

they are able to connect. These are more an exception rather than the rule.

This suggests that her old husband is generally not there and that the perception of him is radically different.

- She feels the relationship and Callum have changed so much that he is like a stranger, a special needs lodger and radically unfamiliar to her now.
- While still viewing herself as a wife, she feels she has been forced to take on a caring role, and a ‘mummy’ role.
- Rose no longer views Callum in a sexual way.

While Callum can see there are changes, there is a sense that he feels that it is still similar to the pre-morbid relationship:

- Callum still feels the relationship is as it always has been, he feels he has never helped out and always been somewhat dependent on Rose.
- Callum notices a decrease in intimacy but feels it is still a possibility.
- He is however questioning that things may not be as he perceives them, but is not sure.

Shared narratives

- Both feel that Callum is more dependent on Rose.

Divergent narratives

- Rose and Callum have different narratives about the complementarity.
- Callum is unaware of the impact of the increased dependence on Rose. He

feels that he has always been dependent on his wife to do things.

- Rose feels communication is now repetitive, futile and tiresome and that there is no longer any conversation. Callum however feels that they are still talking about things as they have always done. The reasons for this change are also divergent, with Rose attributing it to the changes caused by dementia while Callum doesn't.
- Rose attributes the decrease in intimacy due to dementia, while Callum attributes this to reasons other than dementia and still hopes that they may be intimate (unaware of Rose's feelings about intimacy).
- Rose feels she is caring for him while Callum does not feel she is caring for him anymore than she has in the past. Callum is unaware of the impact of caring on Rose.
- Callum feels that his situation is improving, while there is a sense from Rose that she thinks has gotten progressively worse.

COUPLE 3: Albert and Betty

The general features of the couple's relationship and my reflections on how the couple presented in the interviews are described in the Box 5.

Box 5. General features and interview presentation: Albert and Betty.

This couple has been married for 62 years. The beginning of their marriage was characterised by very traditional gender roles where she describes her husband as being dominant. However Betty returned to college and then work in her mid-forties, which she felt changed the dynamics of their relationship and made her more independent and assertive in their relationship; which she feels caused friction between them and which has been a stable feature of their pre-morbid relationship. Both share the metaphor of 'the sweet girl' which represented Betty prior to her returning to education and work. Both share the narrative that the sweetness has been lost. While they have both negotiated a life very separate interests; they are both still rather traditional in their views on marriage. She worked as a teacher and he worked as an engineer. Betty encouraged her husband to retire early as he was unhappy at work; and felt that a change would do him good. Albert enjoyed retirement as it meant that he had the time to pursue his own interests like dog walking and carpentry. The interview with Albert was a challenge as he was unwavering in his idea that he did not have dementia. While thinking of

creative ways of talking about memory difficulties he was quite defensive throughout. Betty was a gracious host offering me numerous cups of coffee and making sure that I was comfortable, she was grateful for the opportunity to talk about her relationship.

A description of the themes relevant to this couple is presented below.

Separate but together

It is clear that the pre-morbid relationship is characterised by independence and separateness.

Albert: *Umm, let me think. One of the, umm, highlights, are the ways that we are different. She likes doing her own thing and leaves me to get on with what I want. So if it doesn't bother you, this umm, our relationship is an ideal situation for the both of us.*

Bruce: *So there is something about both liking to be independent and that is what you like, umm, being together but having separate interests?*

Albert: *Yes, we don't do everything together. Actually we hardly do anything together really.*

This sense of separateness is epitomised through both of them having separate spaces.

I guess we have two separate identities, and that's the way that we've managed to get through life and marriage. Somewhat comparatively comfortably in the fact that she doesn't mind, that while she is in there

making cakes, that I'm up in the garden fiddling around with something. (Albert)

Betty feels that he now follows her which is a change from the pre-morbid relationship where they both had separate spaces.

Betty: *Well he does follow me around more recently. He is always underfoot. Uhh, he now comes and sits in the kitchen while I'm doing tasks in here, which in the past he has never done before. That's the only think that I can think of. He is always around.*

Albert is not aware of this and perceives the situation to be similar to how things have always been.

Albert: *...we are together but doing our own things, have our own space you know. That's it in a nutshell.*

Bruce: *What about now, being home alone together; what's that like?*

Albert: *Quiet pleasant. We both do our own things, have our own interests, have our own space.*

Affection and intimacy

Both share the narrative that sex was important until recently and attribute the change to medication side-effects. In attributing change due to medication, they are minimising the impact of dementia. Betty refers to the myth that older adults do not have sex, and that as a couple they had both continued to be intimate until recently, suggesting that they felt dementia had not changed that aspect of their relationship.

Bruce: *Picking up something you said earlier, you have been sexually intimate until quite recently? What has changed?*

Betty: *Umm, nothing really. It is just he can get an erection anymore. Not sure if it's the drugs and he doesn't discuss it with anybody. We discussed it, I feel sorry for him in a way, because it's always been a part of his life. We have always had an active sex life, even though we are old. People think that when you are old you just stop at a certain point, but we have just carried on as we have always done.*

Bruce: *So for you, have things changed since seeing the doctor?*

Albert: *With my wife?*

Bruce: *Yes.*

Albert: *It's hard to say really, I don't think that there is hardly a difference. Umm, there's been a change in sexual intimacy. But I've put that down to the tablets. You lose your libido I think.*

Aging and Ability

Although Betty accepts that Albert has dementia, they both share the pre-morbid narrative about getting older and losing abilities due to aging. This narrative is based on pre-morbid ideas of Albert's abilities prior to dementia. Betty is making sense of the experience of dementia as part of the normal aging process.

Bruce: *So do you think there is a difference in how both of you are anticipating the future to be?*

Betty: *Probably. Umm, well he dislikes the fact that he is losing his capabilities physically and mentally. It's about getting older; he has always been like that. Losing his ability to do things, because he has always been a very active man. Always building, everything in the garden, I mean he has made all of those bricks for the pagoda. He will*

spend hours making things and he's a lovely craftsman. You know the things that he has made over the years. It's been a journey. He was always not liked the thought of not being able to do things. I don't think about things in terms of the dementia, more about in terms of him losing his capabilities. He doesn't have faith in his diagnosis you know.

Betty feels that he is still very able and has not deteriorated much yet, suggesting the possibility of future deterioration, although it is not clear if she attributes this to aging or dementia.

...I sometimes ask him once or twice if he would do little bits of washing up. Little things like that. Just last week I asked him to help as I was running late and he was, well, he seemed quite amenable. He can still follow tasks. Umm, he is still quite umm, he hasn't deteriorated that much yet. You know, he is still rather amenable and very able.
(Betty)

Albert makes sense of his memory difficulties by questioning the motives of the medical profession and is unyielding in his belief that he does not have dementia.

Albert talks about the inner self, which he feels is still intact and that it is only his body that is aging.

Albert: *Well you are on a very pointed subject here! They themselves find it difficult to put a label on it, so why should I accept that it's true? I'm still me, I have declining memory like every other old man around. It's just memory loss. It's not dementia. See, the thing with the medical profession is finding somebody who is on your side, who can look you in the eye and who looks at the inner self rather than my old body.*

Bruce: *The inner self?*

Albert: *Yes the real me. I'm still me! I am just getting older, but all they see is my old body and me getting older. They don't see I'm still here.*

Bruce: *Sounds like that can be quite frustrating and annoying.*

Albert: *Well it is, it's just memory decline nothing else! I'm still capable of doing everything I used to do. I'm just a little slower and sometimes I forget things, but never the important stuff you know.*

However he is able to concede that others may perceive the situation differently.

He creates a dichotomy of his opinion and reality- suggesting that he may be beginning to make sense of his diagnosis.

Bruce: *I'm trying to understand what it has been like for you to experience memory difficulties. What has it been like for you?*

Albert: *You see I wouldn't have thought anything of it as it is what I associate with old age.*

Bruce: *So are your memory difficulties just old age?*

Albert: *In reality or my opinion?*

Bruce: *Mmm, both.*

Albert: *In my opinion it's old age. I understand others think it is something more sinister.*

Things do feel different for Albert as he feels that things are clearer to him, specifically the end of his life - again suggesting that he is seeing things in terms the natural decline in aging. He is struggling to make sense of his experience: While he holds on to his narrative about aging, through the interview he seemed to be questioning if his situation would be any different had he not gone to the doctor.

However he returns to thinking about aging, and that death would be better than aging.

Bruce: *You mentioned earlier that you were not the person you used to be, what does that mean? How is that different from what you used to be like?*

Albert: *Well I can see the end clearer now than I can see the beginning. Do you get the point that I'm making there?*

Bruce: *What does that look like for your relationship?*

Albert: *Well that is the tricky bit. I do not want to be a dithering idiot. I don't want to lose my ability. Obviously I don't want that. But I don't want to do anything that I could have avoided, upon reflection if I hadn't have done that, go see the doctor, I wouldn't be in this position now. But that is with hindsight.*

Bruce: *You wouldn't be in the same position?*

Albert: *Possibly*

Bruce: *Does that mean that you aren't experiencing any difficulties then?*

Albert: *Oh umm, well I just have a standard joke, it's like, umm, I'm alright as long as these two digits here don't give out, because they are the two fingers that change the telly channels. It's a very relevant joke really. I don't want old age. I don't want old age. It's not, umm, how can I put it; I wouldn't care if I rolled over today.*

Caring and looking after

Betty gives the impression that her role has transitioned into a caring role. However when asked if this had transitioned, she felt that she had always been caring for

Albert and thus felt similar to the pre-morbid relationship and is understood as a marital duty.

Betty: *...I think I've become a mother figure as well, since the problems...*

Bruce: *Has that always been the case?*

Betty: *Yes, umm, I think so. I think I've always been a secure safe person for him, but more these days than ever before.*

Bruce: *A mother figure? Is this new?*

Betty: *No, I am motherly. I am a mother figure. I think that it's just worse since I understand what the problem is now. Yes, I feel I'm looking after him more now.*

Bruce: *In his eyes, has your role changed from wife to something else?*

Betty: *Umm, it's hard to say really. No I don't think so actually. I do look after him, but I have always done that a lot over the years. It is the duty of a wife really.*

Betty thinks about caring as being bi-directional where they both work in a complementary way to help each other. She feels that they have been negotiating this mutual caring prior to dementia.

Bruce: *So what is routine then? Today, who did what?*

Betty: *(Laughs). We had breakfast. I have my own upstairs; he used to bring me breakfast every day since I retired. That changed as his knees are bad now and can't do the stairs. I could see and hear him struggling up the stairs, so I said that I'd do my own breakfast. So that changed because of his physical health really. Umm, and I'd help him more since, like walking about in the garden, transporting stuff and that. You know. So I make my own breakfast now. He has his coffee; he doesn't eat in the morning. He makes his own usually, but today I was*

up first so I made it, got that ready for him when he woke up later. Umm, so I always help, doing more so now though, I'll always do it if he is not there. He'll put the kettle on ready for me if I'm not up first too. So we both help each other along like that.

Betty feels that she is more concerned for him lately, but that she has always cared for him. While she is doing more for him, she still ensures that that they both still have dinner together; which gives the impression that to her caring is part of the role of being a wife. She feels that Albert may not necessarily see her as always having cared for him. She feels that things have changed so gradually that some of the changes have gone unnoticed. She resists the idea of her being anything less than his wife.

Bruce: *...I just want to think a little bit more about caring. So you've identified caring more recently, being more of a motherly role in his life. Is this an extension of being a wife, or is it something different altogether?*

Betty: *Umm, I've been caring for him. I like to make sure he is getting the right diet like food wise, like vegetables and things like that. I try to ensure he is getting a varied diet. Although he doesn't eat a lot anymore, but he does like fruit and nuts and things like that. I've always been thoughtful like that, but more so now because he has gone off his food, and I suppose I'm concerned. He doesn't seem to eat much anymore, which is worrying. So now I try to provide little things throughout the day that I know he'll enjoy and eat. And our evening meal used to be important to both of us, so we still try to do this.*

Bruce: *You've said you have to encourage him more lately.*

Betty: *Yes, I never tell him you know, I now just do it, because I know him and I know he needs encouraging, especially now.*

Bruce: *Sounds like you have always been in a caring role, but just more so now?*

Betty: *Yes. He might not think that though, because of sometimes my attitude. Because I've stood up for myself and more independent than he'd like. I've been more aggressive and intense in my independence in no uncertain terms what I'll do if he behaves in a certain way. So here's a move forward for both, it's not really a big change, but just a change in the intensity or level of caring.*

Bruce: *So caring for him is not a new role then?*

Betty: *Right, but some people think of caring as interfering, don't they, or talking or bossing over someone? I still think of myself as his wife. It would upset me if he, umm, if it wasn't so. Things don't change so dramatically, well not yet, but when it changes over a long time, you are simply not aware of it.*

For Albert, the current relationship feels similar to the pre-morbid relationship as she has always been a capable housewife who has always done everything. There is a sense that he may be resisting the idea that she is caring for him as this would have implications for the power dynamics of their traditional marital roles. However this is a familiar pre-morbid dynamic for the couple.

Well there are not many things that she couldn't do around the house, sew, knit, all that. Umm, she is an ideal wife really in the sense that I never had to do anything as she did it all. But she is very strong willed. She can be domineering if I were to let her, or if I were to be the submissive kind; which I am not. (Albert)

Betty understands caring in terms of always having been “quite a good organiser and [kept] things running fairly smoothly for him”. Albert shares this narrative, particularly for organising his medication. While this may be perceived by some as

caring, he seems to perceive this as her having better organisational skills. This is a shared pre-morbid narrative and so, although he is more reliant on Betty, he feels this is the same.

Bruce: *So if we forget the label, thinking about the timeframe, have you noticed any changes in your memory?*

Albert: *... I would say I'm not the person I was. I'm still me inside. I don't sleep well now, whereas I always slept well. But I've done the Google of the medicine that I'm taking and they have many side effects.*

Bruce: *Medication? What medication?*

Albert: *Oh I don't know, you will have to ask her out there; she takes care of all that,*

Bruce: *So your wife organises all your medication and treatment?*

Albert: *Well honestly, left to my own devices I would probably miss more, but she makes sure my medicine is always ready.*

Bruce: *What's your medication for?*

Albert: *I don't know really; she takes care of it all, ask her.*

Betty has thought about the future and how her caring may evolve and asserts her resolve in caring for him in the future. While thinking about the future is difficult, she is able to face the future and caring based on her pre-morbid feelings:

Betty: *...I've told him "You will live here in our home until you die; you are not going to a nursing home".*

Bruce: *So you've given the future some thought then?*

Betty: *Yes, I want him to be happy here in our home. It upsets me to think that he might go away. You know either to a home or to die. I don't want that to happen (tearful).*

Bruce: *Are you alright?*

Betty: *I am alright. It's difficult to think about the future. I want it for his sake really above my own you know.*

While Albert is aware he is reliant on Betty he is not aware of the impact on her. He is struggling to think that she would want to care for him when he 'deteriorates' and is unaware of Betty's position that she will care for him. His fears about the future suggest that his idea of caring involves being incapacitated and fully reliant on Betty; which would feel different to the pre-morbid relationship based on independence and separateness, and thus seems to resist the idea of being cared for.

Again, who knows what she thinks. It's hard to say really. But if you were to ask me if there were any one thing that I could do if I could see the future and I thought I don't want that, I don't want to be sitting like, umm, like that father in the TV program I just seen. If I've got any choice in that, I want to be, umm, wake up dead one morning rather than go through this deterioration. Whether she would like looking after me in that position I am not sure. I don't want to be looked after like that. (Albert)

Well, uhh, there are not that many people lining up to deal with what my future is going to be, and I can't imagine her clapping her hands and saying I love you, with me, umm, with him sitting there drooling. She wouldn't want that. I don't think she is that daft. I don't want that either. Like I say, I don't know, you must know what her thoughts are as you have already spoken to her (laughs) (Albert)

Effect on wife

Pre-diagnosis Albert became increasingly aggressive that she had considered leaving the relationship. There is a sense that she is confused and frustrated by how he seems to blame her and the faith that she has put in treatment to manage these behaviours:

Betty:*We have also gone through some funny, strange, umm, well he's settled down now since the medication. That has settled him right down.*

Bruce: *Funny? Strange? What was he like before the medication?*

Betty: *Oh I could have walked out. He was terrible. He would interpret things completely different to what really happened. And I think he still believes it now! I was uhh, one instance, I was preparing vegetables in the kitchen using a small kitchen knife. I can't remember why he lost his temper but he grabbed me and pushed me up in the corner against the kitchen sink. And uhh, and wrestled me to the floor and then afterwards, I told him that if he ever did anything like that again I would tell the children. Because he was getting aggressive, out of control and he grabbed me by my throat two or three times, but after he relates stories that it was in reverse, as if I had done it! He said I wrestled him to the floor and tried to attack him with the knife. It was completely the opposite of what actually happened.*

She believes that there has been an improvement in his behaviour since the treatment, and that this has positively impacted her sense of well-being.

Betty: *Umm, but since he's been on the medication I am more relaxed, my hair has stopped falling out, the rash has gone, my tummy has settled. That made me ill you know. Now the aggression has settled things are better but still different to how it used to be in the past. He's*

umm, more amenable now, which quite surprises me sometimes. He was never amenable even before the difficulties.

Although Albert could concede that Betty and the family may have noticed a difference in his behaviours, he concluded that it was just an opinion that he did not agree with - suggesting that he is unaware of changes and impact of his behaviours:

Albert: *The whole family thought that my behaviour was changing, but you would have to ask them. We all have our own opinions.*

Bruce: *It sounds as if your wife and family had noticed some changes in your behaviour.*

Albert: *Well, that is their perception. I wasn't really aware of any changes to be honest. I mean I am still me.*

Summary

A summary of the themes can be found in Box 6.

Box 6. Summary Albert and Betty

Perception of continuity/discontinuity

Both Albert and Betty feel the relationship generally feels similar to the pre-morbid relationship, despite changes :

- The aging and loss of ability narratives feel similar to the pre-morbid relationship.
- Betty feels she is caring more for Albert than before, but that she has

always cared for him and thus feels similar to the pre-morbid relationship.

Albert feels that Betty has always cared for him.

- For Betty the future thought of caring is based on her bonds of love and affection for her husband
- Both still engage in behaviours such as evening meals together.

Shared narratives

- They both share the narrative that intimacy was an important part of their relationship and have noticed a change and attribute this change to due the effects of medication.
- Both share the narrative around aging and the loss of ability and attribute the changes in their relationship due to the normal process of aging.
- They both seem to actively resist being a carer or being cared for and view caring in terms of Bettys better organisational skills.

Divergent narratives

- Albert is unaware that Betty is committed to caring for him. He resists the idea of being cared for as it would mean needing to be fully reliant on her.
- Betty feels that Albert is more dependent, while he thinks that they are both still doing their separate things as they have always done.
- Albert is unwavering in his belief that he does not have dementia while Betty has accepted that he has dementia.

- Treatment has brought changes to Albert's aggressive behaviours, which is a positive change for Betty. Albert believes his behaviours haven't changed.
- While Betty feels that some of his behaviours are a mere intensification of his pre-morbid personality, they have a negative impact upon her. Albert is not aware of the impact of his behaviours on her.

DISCUSSION

The primary aim of the research was to explore the extent to which each person in the couple had a sense of continuity/discontinuity in their relationship. The secondary aims were to explore the PWD's awareness of their spouse's experience of the relationship and to explore whether the sense of continuity/discontinuity is shared within the relationship

Aim1. Perceptions of continuity/discontinuity

Continuity refers to the way that couples respond to the changes in their relationship. A continuous relationship is one where changes have not led to a radical re-appraisal of the relationship or their spouse, where a discontinuous relationship would be where they have.

All participants had an awareness of change within their relationship and within the PWD. It seems that the PWD's had a less clear sense of how things had changed. In the case of Callum and Rose; even though he was aware that things were different, he did not share the perception of discontinuity. In the other two couples, both perceived continuity- They were aware of change within themselves and the relationship, but this awareness tended to be vague and were less aware of some changes. None of the PWD's expressed a sense of discontinuity.

While a couple's sense of overall continuity seems to be based on the pre-morbid relationship, there seems to be some aspects that may feel different. This was evident where

Rose felt that the relationship had a general sense of discontinuity, but there were times when the relationship and Callum still felt the same (albeit less frequently). This seems to reflect the findings by Chesla et al. (2004) for spouses that felt that the PWD had changed and less able to reciprocate but was still accessible at times. Thus perhaps there may be an overall feeling of discontinuity there are still parts of the spouse and relationship that feel the same but transformed. The implication could be that the spouse may act differently toward the PWD in situations where their spouse/relationship feels the same. This may confuse the PWD who may not know the reasons to their partner's differential treatment. Perhaps this could explain why Callum felt the relationship was quite continuous but was questioning if his wife felt similarly.

Work by Achiampong (2011) proposed that spouses who perceived continuity were more likely to use their pre-morbid knowledge of the PWD to understand their difficulties rather than relying on a medical/diagnostic explanation. This is evident with both wives where there was a general sense of continuity. For example, Hazel used her view of her husband to understand some of his current behaviours, such as him never wanting to spend money, do gardening, and still feeling positive about him; all of which had pre-morbid origins. For Betty, sharing the narrative on aging, capabilities and intimacy were all based on narratives held within the pre-morbid relationship. In the example of Rose and Callum, it is evident that Rose holds a more medical perspective – which was shown in her insistence that Callum go to the doctor to be assessed and her being the one liaising with professionals.

Hellstrom et al. (2007) showed that couples worked together at sustaining a nurturative relational context. For example, Hazel and Betty both worked at promoting the joint continued engagement in their previous lifestyle (e.g. belonging to the sports clubs, and continuing to have separate interests or have dinner together, respectively). This was not the case with Rose, who felt that the pre-morbid bonds of intimacy were now distasteful. These wives who perceived more continuity also made efforts to continue physical displays of affection from their pre-morbid relationship. Thus continuity in relationships may be associated with positive efforts to maintain the quality and closeness of the relationship.

Aim 2: Shared and unshared narratives

Each couple had negotiated and held a shared narrative/identity for their pre-morbid relationship. Edgar and Hazel's identity was characterised by activity and family, Callum and Rose's by a work identity and distinct spousal roles and Albert and Betty's by separateness and independence. Where these identities were considered to remain intact for the most part, such as with Edgar and Hazel and Albert and Betty, there was a sense that the relationship felt continuous for both partners; however this was not the case for Callum and Rose. This is consistent with findings that a strong couple identity enhances marital outcomes and may moderate the impact of stress (Badr, Acitelli & Taylor, 2007). It seemed that when couples feel that their relationship is continuous, they have the space to hold multiple narratives about their relationship (not all are shared), and are able to think about the larger dynamics of the relationship rather than immediate problems.

Couples who hold shared narratives based on their pre-morbid relationship tended to perceive their relationship as continuous. Edgar and Hazel both share positive feelings about one another and the strong foundation to their relationship; which gave the couple the sense that the relationship still felt the same despite changes. For Albert and Betty their shared pre-morbid narratives about aging and abilities provided a shared structure to understand their experience, and have a sense that their relationship still felt similar despite changes. Perhaps sharing positive pre-morbid narratives may help the couple better face the changes and new narratives that emerge through the progression of dementia.

When the pre-morbid narratives were no longer shared, there was an increased sense of discontinuity on the part of the spouse who felt the narratives had changed. For example, Rose and Callum held different narratives about a core feature of relationship no longer being complementary. This is consistent with findings by Chesla et al. (1995) and Gladstone (1995) that changes in the feelings towards the PWD is associated with changes in their relational identity.

Where the changes to the relationship create new narratives, it appeared that couples who were able to share narratives about these changes, tended to perceive their relationship as more continuous than those who did not. For example, both Edgar and Hazel share the narrative that Edgar is doing less these days and becoming more dependent on her. There seemed to be a sense of reflexivity in their joint understanding of these changes. In the case of Albert and Betty, both shared the narrative about the importance of intimacy in their

relationship and how the changes in intimacy were due to medication, thus moderating the meaning ascribed to dementia. However, in the case of Callum and Rose, she had new narratives about intimacy and her husband being likened to a special needs lodger and a stranger. Callum did not seem to be aware of, nor share these new narratives. Callum also felt that he was getting better, while Rose felt that things were getting worse.

While all wives felt they were caring for their husbands, all the husbands tended to hold divergent narratives about being cared for. This could be that they all held traditional roles, and could thus be preserving their male identity. This may suggest that the PWD may not be aware of the effect of caring on their wives.

Sharing new emerging narratives would suggest that the PWD is aware of the changes in his wife and relationship. For example, Edgar is aware of changes in the relationship as he now helps his wife with cooking and ironing as he recognises she is getting tired.

While changes to the relationship may seem intuitive, the implications of changes to their couple identity may be profoundly challenging to the PWD. Molyneaux et al. (2011) found that the changing couple identity posed challenges in how couples adjust to the progressive changes. The sense that their spouse has changed towards them and not knowing why may prove to be confusing or distressing for the PWD. This highlights how couples communicate the feeling of discontinuity and change in their relationship. While Callum believed that his relationship felt continuous, he was questioning if his wife felt the same. This could suggest that reflexively he was aware that his wife felt the relationship had changed, but this had not

been openly discussed. This also seemed to be the case with the other two husbands who felt their wives were not sharing everything – and in both cases, the wives were not. Patterns of communication fraught with feelings of futility or not wanting to share, may impact a couple's ability to maintain shared narratives and sense of continuity. This highlights the importance of continued conversation in sustaining a sense of couplehood, shared understanding and agreement between couples (Hellstrom et al., 2007).

Shared stories that become divergent could affect the couple's dynamics: There could be increased division between the couple and possible power imbalance, such as with Rose and Callum around the theme of communication, and Edgar and Hazel, where Hazel felt she is responsible for everything. Perhaps divergent narratives are experienced as finite opposite positions rather than equally valid alternative narratives. Perhaps reconceptualising divergent narratives as being equally valid, may allow each partner to acknowledge and validate their spouse's position. Perhaps shared narratives lends itself to keeping their couple identity more intact than divergent narratives, thus allowing them to have a sense of continuity in couplehood identity; which may better equip the couple to adjust to dementia-related changes. When the sense of discontinuity is not shared, there could be a sense of frustration, confusion and futility in engaging for both spouses, as seen with Callum and Rose. This finds resonance with Svanstrom and Dahlberg's (2004) findings on feelings of imbalance and futility.

This research shows how spouses may perceive change in their spouses; and if they are able to see each other's position. For example, Rose seemed to be quite blaming and understood Callum's behaviours as being intentional. This attribution of blame resulted in feelings of frustration for both Rose and Callum. This relationship seemed to be characterised by a lack of shared acknowledgement of each other's experience. Rose appeared to be unable to view his behaviours as not being purposeful, while Callum did not seem to be aware of the impact on his wife. This is consistent with work by Walters et al. (2010) where caregivers tended to be more empathetic towards the care-receiver, if there was a sense of continuity. Thus in a relationship felt to be less continuous, that relationship may be characterised by a less empathetic caring experience as seen with Rose and Callum. This is consistent with findings by Achiampong (2011) where spouses who perceived their relationship to be discontinuous do not use the PWD's pre-morbid characteristics to understand their current behaviour.

Further reflections on continuity/discontinuity

Previous literature has suggested that continuity might moderate the emotional impact of dementia; and that it has been linked to differences in the way that spouses approach the caring role. This current study supports some of these suggestions. All of the wives acknowledged caring aspects to their relationship, however those wives who perceived more continuity in their relationship seemed to have more positive experiences of their caring role and saw it as an extension of their role as wife. This is consistent with work by Walters et al. (2010) who found that a sense of continuity increased a caregiver's tendency to empathise

with their partner; and with work by Badr et al. (2007) that suggests that a positive understanding of caregiving may be a result of viewing the relationship as an extension of oneself. Thus, a more empathic spouse may be seen as more warm, caring and a complementary partner in care rather than a carer void of such feelings or connection. Rose felt that caring was also an extension of her role, but felt caring had been forced upon her. Perhaps the sense of discontinuity created by no longer having the sense of couplehood may be exacerbated by the feeling of obligation or being trapped. This is consistent with the ideas proposed by Walters et al. (2010) that discontinuity is associated with a feeling of being captive to the caregiving role. Rose was the only wife who had considered residential care. The sense of discontinuity seemed to have eroded the couple's identity to the point that she felt estranged from her husband. Perhaps this is similar to Svanstrom and Dahlberg's (2004) notion of homelessness, where she now viewed her husband as a stranger and a lodger. This is also consistent with work by Lewis (1998) and Walters et al. (2010) who proposed that spouses who perceived discontinuity tended to think about caring as controlling and restrictive and viewed their spouses in ways that were objectifying and depersonalised. Seeing Callum as a stranger and lodger, may be Rose's way of coping, which seems consistent with findings by Chesla et al. (1994), Lewis, (1998) and Walters et al. (2010), who suggested that emotional detachment may be a means of managing the stress caused by witnessing the deterioration of a loved-one.

The quality of the pre-morbid relationship moderates how couples may experience change in their relationship. For example, one narrative that Betty held about her current relationship

was how she felt Albert was more amenable now than before. This highlights how change may not always be perceived negatively by the couple.

In addition, the quality of the pre-morbid relationship and couple identity may determine how quickly partners and couples transition from a sense of continuity to discontinuity. The relationship between Rose and Callum was characterised by less warmth, rigid roles and more practical aspects of being in relationship. They appeared to have fewer shared pre-morbid narratives, in comparison to the other couples. For example, while both felt that Callum was more dependent, he was not aware of the impact of this on his wife and felt he had always been dependent on her and thus did not perceive a change. It may be that couples who are more collective in their pre-morbid relationship may have a stronger sense of identity as they face illness; while couples who are less collective are less responsive to each other's needs (Badr et al., 2007). Perhaps if the pre-morbid bonds are weaker, they may be likely to dissolve quicker under the challenge of dementia; and that if the pre-morbid relationship is less strongly characterised by a sense of partnership in facing life's challenges, it is more likely that the carer will move more quickly to the sense of being an individual, rather than belonging to a couple, described in some of the literature about discontinuity (Gladstone, 1995; Kaplan, 2001).

This study may shed further light on the nature of continuity/discontinuity. While helpful, perhaps relationship types (Chesla et al., 2004), typologies (Kaplan, 2001) and patterns (Keady, 1999; Keady & Nolan, 2003) do not adequately access or illuminate the complexity

of couple dynamics. Perhaps continuity is influenced by the multiple narratives that spouses hold about themselves, their partner and their relationship. It also highlights the possible importance of the pre-morbid relationship in understanding why some spouses may perceive discontinuity more readily than others.

Strengths, limitations and future research

The analysis process was conducted by me. However to enhance credibility, the interpretations were discussed and agreed upon through supervision. I also completed a reflective diary after each interview, which was used in the coding process; allowing reflection on possible biases. To aid transparency, a worked example has been provided (Appendix 5)

The underlying theoretical position of systemic psychology may have created a bias in the way that the data were interpreted, thus interpretation of the findings needs to consider the bias that this may have created (see Appendix 6, for reflective discussion). However I believe that such an approach allowed the couples to reflexively think about the impact of dementia on themselves, their partner and their relationships. It is an approach that is increasingly being recognised to having value in studying the effect of dementia on couples (Hellstrom et al., 2007; McGovern, 2010).

While most previous research had interviewed couples together; this research interviewed the couples separately, which may have allowed for the PWD's voice to be heard more

clearly. Furthermore separate interviews allowed exploration of the impact on the PWD of an awareness that the relationship had altered in a way that a joint interview is unlikely to have done.

Leading on from this, future research may investigate the impact on the PWD in a discontinuous relationship who has awareness that things have changed, but lacks a clear sense of why they have changed; and what the impact on the relationship would be. Our sense of self and personal identity depends heavily on how others react to us (Gelech & Desjardins, 2011). Dementia challenges the sense of identity and it may be more difficult to maintain a sense of identity if it is no longer being affirmed by spouses.

The current study also suggests some directions for the research on continuity/discontinuity from the care-giver's perspective. It suggests that the pre-morbid relationship may be important in understanding why the perception of discontinuity occurs to some care-givers more quickly than others.

Clinical implications

Clinicians should aim to understand the pre-morbid and current relationships, because the current study adds to the growing literature on the important role they play in moderating the impact of dementia. For example, stress, depression, reduced quality of life and less satisfaction from caring is associated with poorer pre-morbid relationships (Ablitt et al., 2009). Clinicians should question the position that change is experienced and felt as

stress/burden. The current study suggests some more specific areas on which clinical work could focus: These may include working with the caregiver on how they feel towards the care-receiver and about their role as carer. Other work could be with the PWD and how well they understand the changes that are occurring in the relationship and the impact on their spouse, and work towards acquiring ways of validating each partner's experience. Clinical work could also focus on assessing how couples communicate the sense of continuity/discontinuity to their partners; and may include working with the couple to identify communication patterns and strategies that may afford them a better shared understanding of each partner's perspective. Couples could be given the opportunity to engage in couples therapy, facilitating an exploration of their shared and divergent narratives and encouraged to see divergent narratives as equally valid. Couples can be encouraged and facilitated in ways to maintain aspects of their relationship that are important to them.

What this paper adds

- Couples who held shared narratives based on their pre-morbid relationship tended to perceive their relationship as continuous.
- Each partner can hold multiple narratives of their relationship and their partner, not all of which may conform to their general sense of continuity.
- When the pre-morbid narratives were no longer shared, there was an increased sense of discontinuity on the part of the spouse who felt the relationship had changed.
- Couples who were able to share new narratives about changes tended to perceive their relationship as more continuous than those who did not.
- The perception of relational change was partly determined by the quality of the pre-morbid relationship and was not necessarily perceived as being negative.
- How couples communicate the sense of continuity/discontinuity may have implications for the PWD. This highlights the importance of continued conversation in sustaining shared understanding and agreement.

Personal Reflections

As a means of transparency I felt that it was important to provide you some personal reflections on the research presented. I found the research a particularly interesting process. I struggled with how best to represent the lived experience of the couples and to do justice to their experience. In thinking about this, I struggled with issues such as presenting emergent themes versus presenting couples as case studies. My initial analysis did follow the standard IPA format in emergent themes. However while interesting, it was felt through

supervision that the depth and complexity of each couple was lost in this general approach. However, due to word limitations this interesting piece of analysis was not able to be included. This made me reflect further upon the points made in paper 1, about the state of our knowledge being explicitly and implicitly impacted by larger systemic forces.

In writing I became explicitly conscious of the points presented in paper 1. While writing I was struck by how difficult it is to present a paper that is written neutrally. I am aware that at times this paper may fall trap to those ideas presented in paper 1 and acknowledge that my research may be read in many different ways. I do however feel that the use of the position statement and this reflective piece may help the reader contextualise the findings, or at least at minimum be more aware of my position.

While I am particularly systemic in my outlook, I am aware that this way of thinking may privilege certain ways of looking at relationship. For example, it may focus on process, strategy, structural aspects of relationships and thinking about the person-in-context. In writing I made attempts not to fall trap to these biases. However, systemic ideas are fundamental to my paper in thinking about reflexivity and the circularity of the experience of dementia on relationship. My reflections are not to excuse my biases, but simply to make them transparent.

While I was struck by how different each couple was and how each of them constructed the meaning of dementia, I was also surprised to see the similarities in their experiences. I was personally pleased to see that two of the three couples saw caring as an extension of the

marital role and not necessarily as a burden. While I appreciate that the experience must be stressful and may be perceived as a burden for some, I was clear from the start of the project that I did not necessarily prescribe wholly to the idea that the caring relationship could wholly be positive or negative, but more likely somewhere in between. Of course it could be the systemic focus of trying not to view the situation as problematic unless done so by the couples, was the driver behind my position. In thinking about the narratives and stories couples hold about themselves, their spouse and the relationship, I was struck by how stories that were not shared were felt to be opposing – of course my systemic bias of multiple stories and narratives were fundamental in conceptualising how the stories couples have may impact the way that they were making sense of the experience of dementia on their relationship.

As a male researcher I was aware of the potential for the possibility of transference related to my gender such as perceived alliances with the husbands and the impact this may have on the collection and analysis of data. In one of the interviews this was evident when the husband was asking me personal questions about my marriage and was attempting to contextualise his experience in comparison to mine. I was also aware that gender may affect the conversations about intimacy and sex when reflecting upon the impact of dementia on their relationship. I had reflected whether the husbands would not be as open about discussing changes to their relationship as a means of preserving their masculinity, or the potential for wives of that generation to feel uncomfortable discussing intimacy with a male. Interestingly all the couples were open to talking about sex and intimacy. As a clinical

psychologist I felt I was in good stead to be able to manage any potential difficulties that may have arisen by couples talking about the changes to their relationship. I was aware of the possible impact of working with people in a research capacity as a clinical psychologist. I reflected upon the possible impact of people attempting to use the research interviews as therapy and being personally aware of my approach and the differences between a research interview and a clinical session. In the interest of transparency and my training in systemic approaches I felt it was important to be transparent about this and punctuate this at the joint information session and again at the beginning of the interviews, thereby inviting conversation with the research participants and allowing clearer expectations from the outset.

Finally I reflected upon the labels ascribed to research participants, such as ‘well spouse’ or PWD. While I personally do not like labelling a person with dementia with an abbreviation, I have done so out of consideration of word count and it also being an accepted label. Likewise the use of ‘well spouse’ poses a dilemma in that it seems to stem from a medical model and locates health in the spouse without dementia with the underlying pejorative assumption that the person with dementia is not healthy.

Conclusion

While couples may have an overall sense of the continuity/discontinuity, each partner can hold multiple narratives about their relationship and their partner, not all of which may conform to the overall sense of continuity or shared by both. Couples need to adjust to

change in previously-shared narratives and to their identity. Sustaining shared narratives may assist couples in facing the relational challenges of dementia. Spouses may hold multiple narratives; which may impact the PWD's sense of couplehood. The perception of change is partly determined by the pre-morbid relationship, and not all change is perceived as negative. The pre-morbid relationship may be a factor in how quickly a couple moves from a position of perceived continuity to discontinuity. While some spouses may view caring to be an extension of their role, others may experience this as feeling trapped, particularly when they perceive less continuity. Couples with shared narratives about their relationship and the experience of dementia, may increase their sense of empathy, partnership and continuity compared to those couples who don't, and may equip them to manage the challenge of dementia.

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APPENDIX

Appendix 1. Ethics Approval

Appendix 2. Recruitment Pack

- **Recruitment Flyer**
- **Contact Consent Form**
- **Consent Form**
- **Patient Information Sheet**

AN EXPLORATION OF COUPLEHOOD AND DEMENTIA



Do you know a couple that has dementia or memory problems?

Researcher: Bruce R. Pereira

Supervised by: Dr Jo Nicholson, Dr Jan Oyeboode, Dr Gerry Riley

The couple can not be considered if they meet the following criteria:

- ⓐ Couples who are currently diagnosed with other severe mental health disorders, or learning disabilities.
- ⓐ Where one partner is institutionalized.
- ⓐ Couples who do not speak English.
- ⓐ Couples who are unable to make satisfactory arrangements for the supervision of the person with dementia while the person without dementia is being interviewed.

If you need further information, please contact:

Bruce Pereira
Clinical Psychologist Trainee
Tel:
Email:

I am currently looking for couples to participate in my doctoral research project.

The research has received approval from the Birmingham and Solihull Ethics Committee and is sponsored by The University of Birmingham.

- ② I am looking to talk with 5 couples about their experience of dementia.
- ② The interviews will last approximately 90 minutes.
- ② Couples will need to attend an information session prior to the interviews to ensure they understand what the research entails.
- ② Interviews will be audio recorded.
- ② Couples will be reimbursed for travel expenses.

The objectives of this research are to:

- ② Explore the extent to which each person feels the current relationship feels similar to, or different from, their relationship prior to the onset of the dementia.

- ② Explore their awareness of the other's experience of the relationship.
- ② Explore whether the couple have a shared sense of their relationship.

In order to be considered the couple must meet the following criteria:

- ② Couples must be living with each other prior to the diagnosis
- ② One must currently be accessing BSMHFT services for dementia.
- ② Must have the capacity to provide informed consent.
- ② Couples should be aged 50 or older.
- ② Couples should have been in the relationship for a minimum of 10 years.
- ② Both should be aware of diagnosis.
- ② The person with dementia should be male



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CONTACT CONSENT FORM

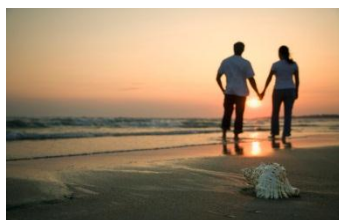
Title of Project: An exploration of couplehood and dementia.

Research Ethics Committee Number:

Name of Researcher: Bruce R. Pereira

This is to confirm that _____ has given permission for me to provide their contact details to Bruce Pereira, so that he tell them more about the above study.

Signature _____ Date _____



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CONSENT FORM

Title of Project: An exploration of couplehood and dementia.

Research Ethics Committee Number:

Name of Researcher: Bruce R. Pereira

1. I have read and understand the information sheet for the above study. I have also had an information session with my partner where the research was explained. I have had at least 1 week to consider the information, ask questions and have had these answered satisfactorily.

☐

2. I confirm I am taking part of my own free will.

☐

3. I understand that withdrawing from the study at anytime will have no effect on any of the NHS care that my partner or I are receiving.

☐

4. I agree to my interview being audio recorded and for these recordings to be transcribed word-for-word.

☐

5. I understand that the information I provide will remain anonymous. There will be no opportunity for my responses to be linked to me.

☐

6. I agree to the use of direct quotes from my interview in the thesis and any future published reports.

☐

7. I give the research team permission to contact my care coordinator if I become very distressed during the research.

☐

8. I give consent for the researcher to contact social services if there are risk concerns.

☐

9. I agree to take part in the above study.

☐

Participant Name: _____ Signature _____ Date _____

Name of person taking consent/Researcher: Bruce R. Pereira

Signature _____ Date _____



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BIRMINGHAM

PARTICIPANT INFORMATION SHEET - Part 1.

Title of Project: An exploration of couplehood and dementia.

Researcher: Bruce R. Pereira

You are cordially invited to take part in a study exploring the effect of dementia on couple relationships.

I am a Trainee Clinical Psychologist currently doing my Clinical Psychology training through the University of Birmingham. This research will be submitted as part of this training. This sheet outlines information on this research. I would be grateful if you and your partner would read through the information to help you decide if both of you would be interested in taking part.

I am supervised by Dr. Gerard Riley and Dr. Jan Oyeboode from the University of Birmingham and Dr. Jo Nicholson from Birmingham and Solihull Mental Health Foundation Trust.

What is the purpose of this research?

The purpose of this research is to:

- ❖ Explore couple relationships when a male spouse has a diagnosis of dementia.
- ❖ Understand how close relationships change or stay the same in the light of dementia.
- ❖ Understand how couples make sense and meaning of dementia.

What will happen to me if I agree to take part?

- ❖ Your care coordinator will provide your contact details to me.
- ❖ I will contact you to set up an information session. During this information session, I will review this information sheet with you. You and your partner will have an opportunity to ask questions about the research. The date and time of the information session will be mutually agreed upon. This could be your local NHS clinic, your home or suitable venue of your choice. After the information session you will have 1 week to decide if you and your spouse would like to take part.
- ❖ After 1 week, I will contact you by telephone to see if you want to take part. If both you and your partner choose to take part, a date, time and venue will be agreed for separate interviews. Written confirmation of your scheduled interview will be sent to you in the post. If you choose not to take part, you will receive no further contact from the researcher.
- ❖ Each of you will be interviewed alone. This interview will take approximately 60 – 90 minutes. This will give you the chance to talk about your relationship.
- ❖ These interviews will be recorded using an audio recorder. After the interview, these recordings will be written word-for-word. To protect your identity your names will not appear in the written transcripts or report. Your partner will not get to see what was said in your interview.
- ❖ At the end of your interview you will be given the chance to identify any parts of the interview that you would prefer not to be used.

What do I have to do?

- ❖ You will meet with the researcher as a couple to discuss the information in this sheet to decide if you and your spouse would like to take part.
- ❖ If you choose to take part, then you will meet with the interviewer at an agreed venue to talk about your relationship. This will take about 60-90 minutes. You

and your partner will have separate interviews. Both of you will be asked to sign a written consent form. A copy of this consent form is attached to this information sheet. You will receive a signed copy to keep.

What happens if I have any further concerns?

If you have any further concerns or would like to discuss any aspect of this study please feel free to contact Bruce Pereira:

Post:

University of Birmingham
FAO: Bruce R. Pereira
Edgbaston, Birmingham
B15 2TT

Email:

This completes Part 1 of the Information Sheet. *If the information in Part 1 has interested you and you are considering taking part, please continue to read the additional information in Part 2.*



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PARTICIPANT INFORMATION SHEET - Part 2.

Why have I been invited to take part?

You have been invited to take part as your care coordinator has identified that you or your partner are currently accessing services related dementia.

Do I have to take part?

Taking part is totally voluntary. This information sheet is to help you decide if you want take part or not.

Travel Reimbursement

You will be reimbursed for travel to your local NHS clinic or to a suitable local venue.

What are the possible disadvantages and risks of taking part?

- ❖ It is possible that you may get distressed when talking about how dementia has affected your relationship. You will be given the opportunity to take breaks or reschedule if needed.
- ❖ The researcher is a trainee clinical psychologist and can provide support where appropriate.
- ❖ Other sources of support and services are outlined at the end of this sheet.

What are the possible benefits of taking part?

- ❖ It will be a chance for you and your partner to separately talk about your relationship and dementia. It will be an opportunity for both of you to consider how dementia has affected each other and your relationship.
- ❖ By taking part, you are helping in our understanding of how dementia and memory problems affect relationships. This may help us understand how to support and help couples in the future.
- ❖ There is no direct benefit for taking part in this research.

What happens when the research study stops?

- ❖ No further involvement will be required once the research stops.

Where can I be interviewed?

You can choose from the following three options:

- ❖ In the privacy and comfort of your own home. We ask that you are able to meet in a quiet and private place in your home away from your partner.
- ❖ In the NHS clinic where you currently access services for dementia or memory problems.
- ❖ In a suitable local venue of your choice.

What will happen if I do not want to carry on with the study?

- ❖ That would be fine. You are free to choose to not take part or withdraw from the study at any time.

What if there is a problem?

- ❖ It is unlikely that there will be any problems. If you are distressed during the interviews, the researcher will be able to provide support. You will also be given the option to stop the interview and reschedule.
- ❖ In the event of severe distress or health problems, the researcher will offer to contact the research team or your care coordinator to determine the best way to provide support to you or your partner.
- ❖ You and your partner can also seek additional support by contacting your care coordinator, GP or your local NHS clinic. Additional services and supports can be found at the end of this sheet.
- ❖ In the event that you disclose something that suggests a risk to yourself or someone else, standard protection procedures will be followed, which may include contacting social services. You will be asked to sign the consent form which consents to this information being shared in the event of possible risk. In the event that abuse is disclosed during the interview, the researcher will speak with the research supervisors to determine what sources of support may be appropriate, which may include contacting Social Services.
- ❖ If you have a concern about any aspect of this study, you should ask to speak with the researcher who will do their best to answer your questions. Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from your care coordinator.
- ❖ You can also contact the Patient Advice and Liaison Service (PALS) at:
Email: **Tel:**
Address:

Will my taking part be kept anonymous?

- ❖ You will be assigned a fictitious name as a way to protect your identity.

- ❖ The research will use direct quotes from your interview in the final write up and thesis/reports and thus what you say is not confidential. However, as no real names will be used, there will be no way to link your words to you.
- ❖ You will be given an opportunity to identify quotes from your interview that you would prefer not to be used.
- ❖ Your partner will not have access to the information in your interview.
- ❖ All personal information will be kept under lock-and-key and will only be accessed by the research team.
- ❖ Your information will be stored at the University of Birmingham for 10 years, after which it will be disposed of in a safe manner.
- ❖ Audio tapes will be wiped and disposed of as soon as they have been transcribed.

What will happen to the results of the research study?

- ❖ The results will be submitted to the University of Birmingham as part of the requirement for the Clinical Psychology training course.
- ❖ The results may also be published in journals relevant to dementia or be presented at conferences.
- ❖ A brief summary of the general results will be mailed to you. There will be no identifying information or direct quotes in the summary that is sent to you.

List of Supports and Services in Birmingham and Solihull:

The researcher is not connected with any of these services. They are provided to assist you if you feel that you need extra support. You can also contact your GP, your existing care team or care coordinator for additional support.

Alzheimer's Society

Tel:

Email:

Website:

Birmingham City Council

Tel (General enquiries):

Email address:

Website:

Solihull Metropolitan Borough Council

Tel

Email:

Website:

Birmingham and Solihull Mental Health Foundation Trust

Tel:

Email:

Website:

Dementia UK (Registered charity no: 1039404)

Tel:

E-mail:

Website:

Alzheimer's Society

Tel:

Website:

Patient Advice Liaison Service, BSMHFT

Tel:

Email:

Website:

☺ **Thank you for taking the time to read this information sheet** ☺

Appendix 3. Topic Guide

1. What are you like as a couple?

2. How was your relationship in the past?

Prompt: What do you think your spouse would say?

3. How is your relationship since the diagnosis?

Prompt: What do you think your spouse would say?

Prompt: How has it changed from the past?

Prompt: Do you think your spouse is aware of these changes/stability in how you perceive and feel about your relationship?

4. How do you anticipate your relationship to be in the future?

Prompt: What do you think your spouse would say?

5. How often do you share your thoughts and feelings with your spouse?

Prompt: What sorts of things do you not share with your spouse?

Prompt: How much do you think your spouse shares their thoughts and feelings with you?

6. Is there any part of your interview today that you would prefer not to be used?

Prompt: Are you happy for all the information we have discussed today to be used in the research project?

Prompt: Which parts are you not happy to be used.

Appendix 4. Worked example

- Worked example: Initial noting, searching for themes
- Worked example: Looking for patterns between husband and wife.

Appendix 4. Worked example: Initial noting, searching for themes

<p>Acceptance? Interaction Reflexivity Ability Fear Impact Awareness of change?</p> <p>Interaction Traditional</p> <p>Couplehood/ separateness</p> <p>Continuity?</p> <p>Sense of 'I' Couplehood/we Ability Aging Fear?</p>	<p>Bruce: What kinds of things were there differences of opinions on?</p> <p>3M: Hmm, it's hard to remember.</p> <p>Bruce: Any difference of opinion recently?</p> <p>3M: No not really. Life is what it is and apart from the fact that I don't want to be <u>subdued</u>, <u>but I don't know if she would ever really want that either.</u></p> <p>Bruce: Has there been a struggle for who is 'boss'?</p> <p>3M: No not really. <u>She knew her place.</u></p> <p>Bruce: I see you indicating with your hands almost as if you are both going in the same direction but doing separate things?</p> <p>3M: Exactly. That is it. It has always been like that.</p> <p>Bruce: Do you anticipate it to be like that in the future?</p> <p>3M: Mmm, well there is not much scope for me to change now is there? I don't know really know the answer to what the future holds <u>for me, for us.</u></p>	<p>He forgets? Or would prefer not to talk about such things?</p> <p>Nothing recent either. Is he aware of his wife's feelings about the aggression etc?</p> <p>Subdued: referring to loss of ability? Dementia? Maybe not losing his independence? Losing his place in the home as being 'boss'?</p> <p>Reflexivity: thinks his wife wouldn't want him that way either.</p> <p>Interactions: traditional</p> <p>Hand gestures were important here. Suggested moving in same direction</p> <p>Their sense of togetherness is characterized by moving in same direction but doing things separately.</p> <p>Does he feel he is getting near the end of his life? He is set in his ways? Maybe accepting that he has dementia and that will take away his ability to change/adjust?</p>
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<p>Reflexivity Social Separate activity</p> <p>Sense of 'I' Communication</p> <p>Separate space Separate activity</p> <p>Reflexivity (and lack)</p> <p>Interaction</p> <p>Tolerance? Interaction</p>	<p>Bruce: Let's think about what you think your wife would say about your relationship in the past.</p> <p>3M: Well, did I think she liked it?</p> <p>Bruce: What do you think she would have thought about it?</p> <p>3M: Well, I think that she probably would have liked me to be a bit more sociable. Like I say, I am quite content to be up the garden, fiddling around, or never having to chat to anybody. I like my own company and I'm never bored with me, or never bored with the person I am with.</p> <p>Bruce: So you think she may have wanted you to change? Anything you think she was happy with in the past?</p> <p>3M: I would hope she was happy with it. I don't know really, you would need to ask her. She is still around as I assume she is happy, but I am sure she had her niggles. Maybe things she would have liked to change. I don't know really. Ask her.</p>	<p>Transitions from Sense of 'I' to us.</p> <p>Reflexivity. Again a sense that he feels she wants him to change. The role of change in this couple? This social keeps coming up. Must be an important area of tension? Insular like the wife says? Is this why de doesn't communicate?</p> <p>Level of activity?</p> <p>Reflexivity. When asked he seems to say I should just ask the wife. Still around – is he aware that she wanted to leave? Niggles- suggests pettiness to them? Tensions? Is he aware what they are? Change figures as a central idea with him.</p>
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Appendix 4. Worked example: Looking for patterns between husband and wife

Wife	Husband
Change Traditional Separate activities Challenge to traditional Role of mother Finances Independence Comparison to others Interaction Aggression Sweet girl metaphor Tolerance Communication Attribution Reflexivity Joint activity Social: Separate activity Treatment Impact Family Couplehood/we Sex/Intimacy Diagnosis changed something Aging Wife increasing activity Rituals Sense of 'I' Decreased level of activity Own space Reflexivity (lack) Self-attribution Me time Social? Increased dependence on wife Questioning the diagnosis Ability Acceptance Level of activity Family Activity	Interaction style Interaction Couplehood/we Tolerance Sense of 'I' Separate activities Family activities Joint activities Family Separate activity than became joint activity Attribution Traditional Self-attribution Increased dependence Acceptance Impact Finances Reflexivity Ability Comparison to others Questions diagnosis Aging Reflexivity (lack) Communication Treatment Death Sex/Intimacy Sense of two 'I's' Wife trying to increase activity level Me time Dependence on wife. Fear Separate space Awareness of change

Appendix 5. Publishing guidelines for targeted journal.

Dementia

The International Journal of Social Research and Practice

Appendix 6. Executive summary / public dissemination document

A systemic exploration of couplehood and continuity: Negotiating the meaning and experience of dementia.

This paper describes a qualitative study conducted by Bruce Roland Pereira presented as part of a thesis for submission to the School of Psychology, University of Birmingham for the Doctorate in Clinical Psychology.

Background

Research on dementia has traditionally taken a bio-medical perspective of dementia. Research that has focused on the impact of dementia on relationships has usually been viewed using a stress-burden model. It has frequently been suggested that the relationship between a person with dementia (PWD) and their spouse has a major role in moderating the impact of the dementia on the couple. Thus the overall rationale for this study is based on the suggestion in the literature that what happens in relationships is important to the emotional well-being and self-identity of both parties. There is a suggestion in the literature that supportive and close relationships may be a protective factor when considering the psychological wellbeing of older couples. The quality of the pre-morbid relationship impacts upon the experience of the relationship post-diagnosis. One strand of dementia research relates to the idea of *continuity* in the relationship from the premorbid to the current relationship; and the moderating influence that this may have on the impact of dementia. Continuity refers to how couples respond to the changes in their relationship; specifically to whether or not these changes have or have not led to a climactic point where the spouse or relationship is perceived as being radically and essentially different to the pre-morbid relationship. The idea of continuity of relationships highlights the significance of the pre-morbid relationship and how this may impact on the current relationship.

Aims

These were to explore couple's awareness of change in their relationship and their response to those changes. The secondary aim was to explore the PWD's reflexivity in the awareness of change in their spouse.

Participants

Three Couples were recruited from an older adults CMHT. All couples lived together in their family home in the community. Ethical approval for the study was provided by an appropriate NHS research ethics committee. The husbands presented with dementia, two of the vascular type and one of the Alzheimer's type.

Interviews and Analysis

Each partner was interviewed separately using a semi-structured interview. The interviews were transcribed and then analysed using Interpretative Phenomenological Analysis.

Findings

The findings were presented as three case studies with a number of themes specific to each couple. The focus of the case studies was on the couple's perception of continuity/discontinuity and shared/divergent narratives. From the case studies some general features associated with continuity were discussed:

- Couples who held shared narratives based on their pre-morbid relationship tended to perceive their relationship as continuous.
- Each partner can hold multiple narratives of their relationship and their partner, not all of which may conform to their general sense of continuity.
- When the pre-morbid narratives were no longer shared, there was an increased sense of discontinuity on the part of the spouse who felt the relationship had changed.
- Couples who were able to share new narratives about changes tended to perceive their relationship as more continuous than those who did not.
- The perception of relational change was partly determined by the quality of the pre-morbid relationship and was not necessarily perceived as being negative.
- How couples communicate the sense of continuity/discontinuity may have implications for the PWD. This highlights the importance of continued conversation in sustaining shared understanding and agreement.

References

Hellstrom, I., Nolan, M., & Lundh, U. (2007). Sustaining 'couplehood'. Spouses' strategies for living positively with dementia. *Dementia*, 6(3), 383-409.
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